The Re-construction of Women’s Sexual Lives After Pelvic Radiotherapy

“For a long time it was like a nuclear war zone. Just keep out.....Chernoble......don’t go anywhere near it!”

By

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Abstract

Background & Research Aim
Pelvic radiotherapy creates both physical effects and psychological responses that negatively affect the sexual health of women and their partners. However, the clinical assessment and management of female sexual difficulties does not receive equivalent professional focus as that of male sexual dysfunction after cancer treatment. The overall aim of this study was to explore the factors that influence the clinical assessment of treatment-induced female sexual difficulties within routine medical follow-up. The purpose of this exploration was to identify the key components of a clinical assessment methodology that could be developed to improve the evaluation of psychosexual morbidity associated with radiotherapy for women with pelvic malignancy.

Methodology
This focused ethnography used participant observation of follow-up clinics (n = 69) and in-depth interviews (n = 49) with women, partners and health professionals to collect data. Observation data were analysed using SPSS and interview transcripts subjected to thematic analysis using NVIVO.

Findings
Psychosocial issues were discussed in only 42% of consultations, suggesting that these elements of women’s recovery may not be considered a priority in oncology follow-up practice. Vaginal toxicity (42%) was discussed less frequently than bowel (81%) or bladder (70%) toxicity and sexual issues were discussed in only 25% of consultations. Interview data revealed unmet need in relation to women and couple’s sexual recovery including a lack of knowledge and distress caused by fear of resuming sex, loss of sexual desire, dyspareunia, altered orgasm and reduced sexual satisfaction. Partners felt marginal to what was happening to the women in their lives and were not actively engaged in the follow-up process. Oncology follow-up was considered an inappropriate context for the assessment and management of female sexual morbidity because of the priority to detect disease recurrence and manage acute side effects.

Conclusion
Assessment and management of sexual difficulties in women following pelvic radiotherapy remains a neglected aspect of rehabilitation after cancer and will require developments at both an individual practitioner and organisational level if care is to be improved.
Acknowledgements

There are many friends, family and colleagues who have been instrumental in the conduct and completion of this thesis without whom I would most certainly have wavered, if not fallen by the wayside. However, there are some individuals who deserve a special mention at the end of this stage of what has been an arduous but fascinating journey:

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I appreciate the professional support and commitment of clinical colleagues and hope that these findings will contribute in some meaningful way towards the ongoing development of professional practice and services in clinical oncology.

My grateful thanks to the women and men who gave their time and emotional commitment to this research through sharing their experiences of cancer treatment and being prepared to talk so openly about their personal relationships and sexual lives after cancer. This thesis would not have been possible without you and I hope I have faithfully represented your experiences and their meaning.

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And finally a special thanks to my parents, Ian and Ria White, and to my husband Redouan Maarouf.
While some are forever in my past, their memory will continue to shape both my present and future endeavours.
Declaration

This thesis and the work to which it refers are the results of my own efforts. Any ideas, data, images or text resulting from the work of others (whether published or unpublished) are fully identified as such within the work and attributed to their originator in the bibliography or in footnotes.

This thesis has not been submitted in whole or in part for any other academic degree or professional qualification.

Signed: .................................................................................

Isabel D. White

Date: 30th September 2008
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Chapter 1: Introduction

Increasingly cancer is viewed as a chronic illness as opposed to one that is either cured or rapidly fatal. Research commissioned by Macmillan Cancer Support (Kings College London et al. 2008) has estimated that in the UK the number of people living with or beyond cancer currently stands at two million.

Multi-modal cancer therapy that incorporates surgery, radiotherapy and chemotherapy or targeted therapies has become the mainstay of modern cancer treatment. However, this combination of treatment modalities may come at a price in relation to the number of people who experience treatment late effects months or years after cancer treatment is completed (Rowland et al. 2006). As increased numbers of people survive or live with cancer as a chronic illness, their post-treatment quality of life becomes an increasingly important measure of effective cancer treatment and care. Yet most clinicians focus on the recording and management of acute side-effects and are either unaware or unwilling to recognise the late or delayed consequences of cancer treatment. As there is no national system for recording the more severe consequences of multi-modal cancer treatment, estimates of the prevalence of long-term sequelae, including treatment induced sexual difficulties, lacks precision (Maher & Makin, 2007).

Clearly in the absence of prevalence data and a systematic method of clinical assessment for the late consequences of cancer treatment it also remains difficult to develop and test clinical interventions for the investigation and management of such difficulties.

Sexual well-being is identified as a core element of quality of life for people affected by cancer, particularly those receiving treatment for malignancies of the pelvic organs (Allal et al. 2005; Marijnen et al. 2005; Wenzel et al. 2005). Pelvic radiotherapy creates a number of physical effects and psychological responses that may impact negatively on the sexual health of women and their partners (Flay & Mathews 1995; Bergmark et al. 1999; Juraskova et al. 2003, Jensen et al. 2003). Sexual difficulties after treatment for gynaecological malignancy has received increased attention in recent years, with studies reporting prevalence ranging from 50-80% among women who received pelvic radiotherapy for cervical cancer (Crowther et al. 1994; Flay & Mathews 1995). However, there remains a paucity of information regarding sexual difficulties arising from the multi-modality treatment of women with endometrial, bladder, anal or rectal malignancies (Fokdal et al. 2004, Marijnen et al. 2005, Jephcott et al. 2004; White, 2008).
The magnitude of sexual morbidity associated with pelvic radiotherapy is illustrated by more recent quality of life (QOL) and radiotherapy morbidity studies where women receiving primary or adjuvant pelvic radiotherapy experience greater and more prolonged disruption to their sexual well being (Jensen et al. 2003; Davidson et al. 2003a; Donovan et al. 2007) than women after surgery alone (Leake et al. 2001; Juraskova et al. 2003). QOL studies also highlight the multifactorial and complex nature of female sexuality during recovery from cancer (Leake et al. 2001; Tabano et al. 2002; Juraskova et al. 2003).

The paucity of data on the prevalence of sexual difficulties associated with cancer treatment is further complicated by the presence of both transient and persistent sexual difficulties in the UK adult population as a whole, as reflected in findings from the NATSAL 2000 [National Survey of Sexual Attitudes and Lifestyles] survey (Mercer et al. 2003, 2005). A stratified probability sample of 11,161 adult men and women aged between 16 and 44 years of age took part in this study, with an overall response rate of 65.4%. One immediate difficulty faced in making a meaningful comparison of prevalence rates for specific sexual difficulties between this sample of the UK population and most patient groups within oncology is that a large percentage of people affected by cancer and their partners are over 44 years of age at the time of their diagnosis.

Mercer et al. (2005) used duration of the sexual difficulty and sexual avoidance arising from the experience of difficulties as indicators of severity and demonstrated that the prevalence of self-reported “sexual function problems” were reported by 50% of women and 33% of men. This prevalence rate reduced to 6.2% of men and 15.6% of women reporting persistent (duration of at least six months in the past year) sexual difficulties (Mercer et al. 2005). Interestingly, more women (21%) than men (10.5%) experiencing sexual problems in the past year had sought professional advice and the majority of those questioned identified their general practitioner (GP) as the main source of help. Among those who reported a sexual problem, 32.5% of men and 62.4% of women had avoided sex because of their difficulty (Mercer et al. 2003). The overall numbers of men and women with sexual problems who sought help to resolve their difficulties remains low, giving us an indication of how unusual it is even for younger individuals to approach health care practitioners for help when they have a sexual concern.

A recent systematic review of prevalence studies investigating female sexual difficulty / dysfunction by Hayes et al. (2006) identified only eleven out of 1,248 published studies that met their strict inclusion criteria for research and clinical rigour. These authors found consistent patterns of female sexual difficulties in the published literature and among
women reporting any sexual difficulty 64% experienced low sexual desire, 31% experienced arousal difficulty, 35% experienced difficulty with orgasm and 26% experienced sexual pain. In the studies reviewed 62-89% of sexual difficulties had been present for several months and 25-28% had persisted for six months or more. However there was wide variation (21-67%) in the proportion of women who were distressed by the sexual difficulties they experienced (Hayes et al. 2006).

Hence the “true” prevalence of the different types of female sexual difficulty (FSD) encountered in the general population remains a contentious issue and more recent research by Hayes et al. (2008) demonstrates that reported prevalence rates can be markedly affected by a range of factors including the populations sampled, research instruments selected and measurement parameters set such as duration of FSD, inclusion of sexual distress as a defining characteristic, and the time frame over which women are asked to recall the presence of their sexual difficulty.

Within contemporary clinical oncology practice the assessment and management of female sexual difficulties is often an inconsistently addressed and relatively neglected element of women's recovery and rehabilitation. In my practice as both a cancer nurse and a psychosexual therapist I was interested in the apparent gender disparity regarding the extent to which male sexual dysfunction (mainly erectile dysfunction) associated with cancer was managed by specialist services both within and beyond cancer centres and yet in the centres with which I had clinical links there did not appear to be an equivalent service or systematic approach to the management of women experiencing sexual difficulties. Furthermore, women with treatment induced sexual difficulties did not appear to be referred to specialist psychosexual services to the same extent as their male counterparts. This gender disparity has also been recognised by medical sexologists and a recent editorial in the Journal of Sexual Medicine lamented the fact that compared to what is known about erectile dysfunction, “basic research and education in women’s sexual health problems is decades behind.” (Goldstein, 2006, p.950).

The prompt and accurate identification of disease or treatment related sexual concerns are important if appropriate intervention or further referral is to take place (NICE, 2004a). Yet medical and nursing staff still experience considerable difficulty in discussing sexual aspects of treatment with women (Schover et al. 1989; Jensen et al. 2003) resulting in ongoing distress even when physical problem(s) have diminished (Stead et al. 2003). Fundamental to timely and appropriate clinical decision making and subsequent practice intervention in any health care discipline is the ability to conduct an assessment of patient
need that is both valid and reliable (Janjan et al. 1992). Furthermore, the practitioner, organisational and resource (time, skill and environmental constraints) implications of comprehensive clinical assessment are often underestimated (Thompson & Dowding 2002).

1.1 Defining the Research Problem and Research Questions

The aim of this study was to explore the factors that influence the clinical assessment of treatment-induced female sexual difficulties within routine medical follow-up. The purpose of this exploration was to identify the key components of an integrated physical and psychosexual assessment methodology that could be developed for use in routine clinical practice to improve the evaluation of sexual morbidity associated with radiotherapy for women living with pelvic malignancy. A valid and reliable inter-disciplinary clinical assessment method could promote a more consistent and comprehensive approach to the assessment of treatment related female sexual difficulties, especially where different disciplines are engaged in morbidity evaluation. In order to evaluate the feasibility and potential content of any new approach to the clinical assessment of female sexual difficulties within the oncology follow-up clinic the following research questions were posed:

- What is the nature and meaning of psychosexual difficulties for women who have completed pelvic radiotherapy?
- How does the environment and conduct of radiotherapy clinics influence communication about sexual issues from the women and health professional’s perspectives?
- What are the core elements of an integrated psychosexual assessment strategy?
- What is the feasibility of using an integrated psychosexual assessment strategy in routine follow up within radiotherapy practice from the women and health professional perspectives?

This study sought to understand the current assessment of women’s sexual difficulties within clinical oncology follow-up from the perspectives of women, their partners and health professionals. This thesis presents a comprehensive exploration of what has been, to date, a relatively under-researched aspect of women’s recovery following cancer treatment.
As a consequence this study identifies the challenges inherent to conducting clinical assessment of female sexual difficulties within a conventional model of medical follow-up in oncology. The findings of this research suggest that the way in which female sexual difficulties are socially constructed within the oncology clinic exclude the subjective elements of female sexual expression and fail to adequately capture the meaning and nature of women's changed sexual lives after cancer treatment.

This research offers a synthesis of biomedical and sociological perspectives on the study of female sexuality after cancer. Hence this thesis provides a more thorough analysis and interpretation of the topic than is possible through adherence to any single theoretical perspective. A consequence of this synthesis of perspective is that study findings describe and interpret both the essentialist (functional) and socially constructed (subjective) elements of women's changed sexual lives after cancer treatment.

In adopting social constructionism as the underlying theoretical perspective for data analysis and interpretation I have identified limitations in the application of Foucault's ideas (1973, 1990a, 1990b, 1992) to the comprehensive study of human sexuality. Social constructionism fails to take account of the biological and anatomical realities of pelvic changes created by pelvic radiotherapy and their consequences for sexual function. This omission is not just important theoretically, but clinically where sexual assessment may reveal an organic basis for many of the sexual difficulties experienced by the women in this study. I have proposed that the comprehensive study of female sexuality in oncology requires an integration of both essentialist and social constructionist perspectives (DeLamater & Shibley Hyde, 1998) in order to capture the complexity and abstract nature of the female sexual response in both health and illness.

From a practice perspective this study has identified changes to the content and process of women's sexual health assessment in radiotherapy practice that could contribute towards improving the sexual well-being of all women treated for pelvic malignancy through proposed developments in oncology follow-up practice and service delivery. The findings of this research have the potential to improve clinical assessment of the consequences of radiotherapy on women's sexual well being post treatment, thus creating a greater opportunity for timely and effective intervention or onward referral for women and their partners.

The literature review that follows outlines some of the multiple perspectives which may be taken on sexuality and discusses their relevance for the social construction of female sexuality after cancer treatment, its clinical assessment and management.
Chapter 2: Literature Review

2.1 Introduction

Sexuality as a concept may be viewed through a variety of lenses with the biomedical perspective continuing to dominate approaches to sexual health within medical and nursing practice in western cultures. Congruent with the methodological triangulation discussed in chapter three, this review of the literature offers a theoretical triangulation in constructing sexuality as a complex, abstract and multi-faceted social phenomenon. This literature review places sexuality and female sexuality more specifically, in its socio-cultural and historical contexts in taking a social constructionist view of sexuality. From a practice perspective the clinical assessment of sexual concerns may be enhanced and made more meaningful by understanding the multiple contexts in which sexuality is constructed and reconstructed by those who negotiate the boundaries of its expression. These assessment contexts include:

- **Social Context**: (British) society, the professional and organisational culture of cancer care, and cancer nursing and its construction of sexuality
- **Process of Assessment**: the processes of communicating about sexuality and sexual difficulties (or sex / sexual talk) in health care settings and specialities, including oncology
- **Physical / Functional Context**: the construction of female sexual dysfunction within biomedicine
- **Psychological and Interpersonal Context**: the woman, partner and couple construction of sexuality

The following sections of this literature review echo the elements or dimensions inherent to a comprehensive clinical assessment of an individual’s sexual well-being. Female sexuality will be explored from a sociological perspective using the work of Michel Foucault (1990a, 1990b, 1992) and social constructionist theory more broadly. Women's sexuality will also be viewed from a feminist perspective in addressing the power dynamics that influence and determine dominant discourses within society and its literatures. This review will also address the factors that block or enable effective communication about sexual
issues within health care from both a professional and patient perspective. In addressing each of these perspectives in turn this review aims to explore and articulate the complexities of the context, process and content of the assessment of women's sexual recovery and well-being within clinical oncology practice.

This review was conducted using relevant healthcare, psychological and social sciences databases including: Medline, CINHAL, BNI, and Psychinfo. The search terms used included: Cancer AND Sexuality, Communication AND Sexuality, Cancer AND Sexual Function, Cancer AND Sexual Dysfunction, Cancer AND Female Sexual Dysfunction, Sexual Dysfunction AND Radiotherapy, Vaginal Toxicity AND Radiotherapy. In addition to electronic searching, hand searching the reference lists of key articles was also utilised, together with establishing a number of electronic journal alerts in order to access newly published articles as they appeared in the public domain. Only English language papers were included in the review as translation resources were not readily available. Initially no date parameters were set for the review as I considered it important to be aware of the changes in how female sexuality within cancer care had been studied over time. However, as treatment of pelvic cancer by radiotherapy has undergone significant technical development in the last 10-15 years, the biomedical research in this review was subsequently restricted to contemporary studies from 1990 to the present day in order to ensure the types of sexual difficulties reported in studies were comparable with those likely to be encountered within current clinical practice.

2.2 Theoretical Framework

Despite the influence of social constructionism, both in feminist research and in sociological enquiry (Sarbin & Kitsuse, 1994), essentialism (also referred to as biological determinism) was the first perspective to emerge in defining sexuality, and remains the most influential in western culture even today (Vance, 1991; Oderberg, 2008).

Essentialism views sexuality, and hence sexual behaviour, as natural and determined by genetic, anatomical and physiological mechanisms. It also assumes that behaviours of outward similarity share a common underlying meaning.
In contrast, social constructionism takes the position that an objective "out there" reality does not exist. The work of Berger and Luckmann (1967), among others, challenged the stance of logical positivists in proposing that social objects are:

"...constructed, negotiated, reformed, fashioned and organised by human beings in their efforts to make sense of happenings in the world."
(Sarbin & Kitsuse, 1994:3)

Berger and Luckmann's (1967:15) work concerned itself with the sociology of knowledge; exploring the taken for granted nature of what people consider reality and knowledge. Their work was not only epistemological but crucially explored the social processes by which "...any body of 'knowledge' comes to be socially established as 'reality'." They were interested particularly in the knowledge that people gave meaning to through its use in everyday life and without which society would not be able to function. It was this social creation of shared meaning that Berger and Luckmann (1967:27) termed the "social construction of reality".

Contemporary critics of social constructionism as a theoretical standpoint, such as Giles (2006) point to the conceptual flaws in those who adopt a radical constructivist stance in asserting there are no objective facts in our social world and that everything, including our biology, is socially constructed. However, Berger and Luckmann (1967:30) always maintained that society comprised a combination of both objective facts and subjective meanings. Social constructionism, then, is the process by which shared meaning is achieved. Language and its symbolism is the complex system by which the fluidity and diversity of human experience and meaning is captured, made (to varying degrees) stable and enduring across time and cultures and communicated. Hence culturally and historically context-bound concepts such as sexuality are maintained through the active construction(s) and reconstruction(s) of individuals and groups within society as they engage in their "world of everyday life". It is through our individual and perhaps more significantly, through our social thoughts and actions that we maintain something as 'real' (Berger & Luckmann, 1967). In this way one becomes aware that the world consists of multiple realities and while in the main this is unproblematic, as we meet others who do not share our reality or social meaning it can be experienced as problematic when we are faced with alternative realities that challenge our taken for granted assumptions.

Typically differences in social meanings are experienced through our exchanges with people from different cultures, religious faiths, gender(s), generations or social groupings.
Berger and Luckmann (1967:67) recognised that human sexuality was a particularly apt example of this social plasticity and diversity to the extent that:

“Every culture has a distinctive sexual configuration, with its own specialized patterns of sexual conduct and its own 'anthropological' assumptions in the sexual area. The empirical relativity of these configurations, their immense variety and luxurious inventiveness indicate that they are the product of man's own socio-cultural formations rather than of a biologically fixed human nature.”

It is interesting that in this quote we are presented with an example of gendered language which is itself a socio-historical construction with Berger and Luckmann's (1967) use of the term man's own socio-cultural formations to refer to human, both man and woman's social frame of reference.

In contrast to the essentialist works of 19th century sexologists such as von Krafft-Ebing (Bland & Doan, 1998) and the later works of Kinsey et al. (1948, 1953) and Masters and Johnson (1966), Foucault emerged as one of the most influential social constructionist writers to discuss the issue of sexuality (Weeks, 1992). Foucault was a philosopher and social theorist from the post-modernist school of thought and remains one of the most influential social constructionists. Post-modernism argued that society was characterised by difference as opposed to notions of a social whole and its view of the world is one where there are multiple realities, embracing different systems of knowledge and ways of knowing (Porter, 1998). Foucault was particularly interested in the ways in which knowledge orders social realities and believed that it is the power relations inherent to societies across history that determine which types of knowledge are elevated to the position of truths in constructing our contemporary realities (Porter, 1998:210-211). What is surprising, perhaps, is that despite Foucault's insights regarding this power / knowledge complex, and his discourse on human sexuality, he fails to make any specific reference to gender or the inherent power differentials in social relations between men and women (Shildrick, 1997). As Shildrick argues, it is as if:

“In Foucauldian terms, power operates as it were independently of its sexed agents, as an almost abstract force which differentially impacts on women in a non-necessary way. As a result many feminists have argued that at best Foucault is gender-indifferent and therefore of limited use to the feminist project, or at worst deliberately phallocentric in his concerns.” (Shildrick, 1997: 47)

In medicine and nursing power is exerted through professional and patient interaction and discourse. One of the key ways in which power can be enacted is through the concept of the panopticon and surveillance. Foucault's ideas about surveillance as a mechanism of
social control and reform originated from ideas emanating from the panopticon, a 19th century prison design which enabled surveillance of prisoners without them being aware they were being observed. These ideas were developed further in his work entitled “The Birth of the Clinic” (Foucault, 1973) in which he focused on the role of medical surveillance through development of the clinical gaze. Through the clinical or medical gaze the body is conceptualised as a biological machine, complete with norms of structure and function. In the presence of disease the doctor compares signs and symptoms of disorder with anatomical and physiological norms in order to reach a diagnostic category. In this way the clinical gaze objectifies the body, making the incorporation of psychological or social elements of disease (the illness experience) marginal to the diagnostic process.

Porter (1997) draws our attention to Foucault’s later work in which the concept of “pastoral power” was created to encapsulate that power which practitioners exert through subjectification of the individual. Gaining knowledge of the person’s psychological and social world, through the clinical gaze of therapists and nurses, enables surveillance of the most intimate aspects of people’s lives. While this particular clinical gaze has a different focus, it is no less controlling and has the potential to reach beyond the boundaries of bodily surveillance achieved by biomedicine. I would contend that in both cases, professional power can still be used to exclude the personal experience and self-knowledge of patient groups and individuals (see PT19, section 8.6) particularly those who are vulnerable, marginal in society and thus lack power.

Foucault wrote extensively about relationships between the body and the state and the exertion of power by the state through control of the body. He perceived the sexualised body not only at an interpersonal level, but as a focus for institutionalised methods of social control (Foucault, 1990a). Social control operates through institutions such as the law, religion, the penal system, through medical practice and the structures of the hospital. Foucault explored sexuality as it was shaped by the complex apparatus of social regulation which controls individual bodies and behaviour (Weeks, 1992). Throughout history, sexuality and the sexual health of society had been regulated through law which, until the end of the 18th century, centred on matrimonial relations (Foucault, 1990a). Foucault identified three explicit codes which governed the division between the "licit" and the "illicit" in sexual practices: that of canonical law, the Christian pastoral, and civil law.
Each of these laws centred on matrimonial relations to the extent that:

"The sex of husband and wife was beset by rules and recommendations. The marriage relation was the most intense focus of constraints...more than any other relation it was required to give a detailed accounting of itself...it was under constant surveillance." (Foucault, 1990a:37)

In the two centuries which followed, sexuality and the monogamous heterosexual couple became the norm to the extent that the combined social might of the legal, religious and medical systems turned their attentions to what could be socially construed as perversion (Jessopp & Thorogood, 1988).

Foucault (1990a) also challenged the popular hypothesis that sexuality is repressed at both an individual and societal level. Instead, his critique illuminates the extensive and never - ending discourse on sexuality which has developed in western culture, from the beginning of the 19th century onwards. Foucault was intrigued by the apparent paradox about sex in modern society:

"What is peculiar to modern societies, in fact, is not that they consigned sex to a shadow existence, but that they dedicated themselves to speaking of it ad infinitum, while exploiting it as the secret." (Foucault, 1990a:35)

Medicine as a profession has taken a key role in both the surveillance and control of sexual behaviour and its consequences. This is manifest in the way contraception, abortion, pregnancy, childbirth and sexually transmitted diseases are regulated. Psychiatry, on the other hand, concentrated its energies on deviations from the norm and the appropriate use of pharmacological and psychotherapeutic interventions in the realm of sexual pathology (Jessopp & Thorogood, 1988). This Foucauldian analysis of medical power and control, as manifest through the concept of the medical gaze or surveillance has more recently been explored within a clinical nursing context (Lawler, 1991). Lawler (1991) drew parallels between the control function of the medical gaze and the emphasis on nursing observation, particularly during the Nightingale era. This included the development of the Nightingale ward, a rectangular adaptation of the panopticon mentioned in Foucault’s writings, whereby the nurse enjoyed uninterrupted observation of the ward’s inmates yet was, in turn, under surveillance and therefore under control.

Medical [and nursing] surveillance constructs a system of social norms through the acceptance of a series of ‘normalising judgements’ made by professional experts (Foucault, 1973). Thus power is exerted through the use of professional knowledge to define precisely
what is normal or abnormal. Expressed another way, the power of professional knowledge defines which patient or illness related concerns are considered legitimate versus those perceived as illegitimate. Through the mechanisms of professional practice and language, medical (and nursing) staff exert control over which signs or symptoms are perceived as credible and investigated versus those considered irrelevant and not pursued. An example from this study might be the frequency with which objective symptoms of vaginal toxicity (e.g. vaginal bleeding) are discussed and recorded in clinics compared with the subjective symptoms of sexual dysfunction (e.g. dyspareunia). As I will argue later in this thesis it is through such mechanisms that women come to understand whether and when sexual concerns may be raised with their treatment team and more specifically which sexual concerns are deemed legitimate to request professional assistance with and which may not be. Thus the synergy of medical and nursing systems of practice and language shape the legitimacy of women's symptoms for the purpose of both clinical assessment and treatment.

The challenge to a purely biological status of gender and sexuality dates from the mid 1970s, with Foucault (1990a, 1992, 1990b) taking one of the more radical and influential positions (Vance, 1991). Foucault proposed that sexuality itself was a social construct with no innate "biological drive" or "object of desire", thus leaving little room for a relatively stable historical or cross-cultural concept for even the physiology of sexual expression (Foucault, 1990a). Foucault's (1990a, 1990b, 1992) treatise on the history of sexuality argued that sexuality is both historically and culturally defined. Thus, behaviours which are physically identical may possess different social significance and meaning depending on how they are understood by different cultures and at different times in history (Vance, 1991). Where constructionists differ in opinion it is normally on the extent to which they acknowledge or deny any pre-existent physiological sexual impulse. The more moderate are content to construct the nature of sexual behaviour, sexual identity and object of sexual desire as the consequence of an innate physiological drive.

This middle-ground, Vance (1991) argues, allows for integration of both biological and socially constructed concepts of the body, and its consequences. Martin's anthropological study (1987) challenged the covert cultural assumptions that shape historical and contemporary "scientific" views of women's reproductive processes. In her work Martin (1987) also sought a more honest integration of cultural and scientific perspectives on women's reproductive anatomy through exposing the underlying cultural metaphors that served to alienate women from their bodies. A more recent study analysed historical representations of male and female anatomy in Gray's Anatomy from 1858-1998 (38 editions) and also found
that even the apparent scientific neutrality of anatomy could be contested (Petersen, 1998). Petersen (1998) found numerous examples of gender bias in the ways in which anatomical facts were socially constructed across time. Female anatomy was frequently described in its relation to male anatomy as the standard or norm. Female genitalia was aligned with its male counterparts (clitoris equivalent to penis, ovaries to testes, labia majora to scrotum) with assertions being made that male genitalia had undergone greater development and maturation in representing these sex differences. Furthermore, a greater proportion of text was devoted to descriptions of the penis and testes than that relating to the clitoris and ovaries respectively.

Social constructionists have also challenged the apparent scientific neutrality of the 20th century sexologists in exposing the mechanisms by which patriarchal gender relations are perpetuated through the scientific construction of what constitutes normal and hence dysfunctional sexual expression (Boyle, 1994). An example of the influence of this theoretical position may be found in the controversy surrounding the ways in which female sexual dysfunction (FSD) has recently been represented in both the lay and professional press. The media portrayal of FSD provides a powerful example of the way medical facts can be deliberately misrepresented or constructed to deliver a message that medicalises an aspect of human experience that is culturally within normal limits. FSD and media calls for its pharmacological treatment (search for a pink Viagra) began within days of the American approval of Viagra (sildenafil) for the treatment of erectile dysfunction (Tiefer, 2006). From 1997 to 2004 Pfizer (the pharmaceutical company responsible for the development of Viagra) was one of the main promoters of this new disease entity, FSD, and pursued the approval of Viagra to treat female sexual arousal disorder. John Bancroft, a much respected British sexologist, now based in America at the famous Kinsey Institute, severely criticised attempts to create a new "disease entity" through the "...non-evidence based diagnostic categorisation for women's sexual dysfunctions, based on the male model, and then requiring further research to be based on that structure. Increasingly it is becoming evident that women's sexual problems are not usefully conceptualised in that way." (Tiefer, 2006:0438).

As this example illustrates, social constructionism is important in understanding both the personal and social meanings ascribed to apparently stable reality and experience:

"What is most essentially human is precisely that our lives, women's and men's, are not just determined by biological necessity but crucially also by human action and vision."

(Segal, 1992:10)
Hence, in asserting the premise that human sexuality is a biological, psychological and social phenomenon it is clear that any comprehensive study of sexuality must consider the influence of prevailing political, social and ideological norms as its contemporary context.

2.3 Feminist perspectives on Sexuality

Busfield (1996) suggests that gender, which embraces both masculinity and femininity, can be defined by five key characteristics:

- It is a social construct
- It is binary: denoting male and female, thus limiting diversity
- It is relational: about societal gender relations and their capacity to shape and maintain gender stereotypes
- It implies structural inequality and power imbalances
- It is a linking concept: gender permeates social life, it is integral to understanding individuals, groups and organisations

In her exploration of Busfield's (1996) work, Miers (2000, p.13-15) added a sixth characteristic of gender which is particularly pertinent to nursing practice related to sexuality and that is that gender is also embodied. Gender as an embodied concept permits the incorporation of one's biological sex and recognises the body as a key source of gender significance and identity enactment.

Within the social politics of gender identity, femininity and masculinity are also heteronormative whereby gay male and lesbian identities are problematised within a dominant patriarchy. In femininity, female sexuality is always constructed as heterosexual with the expectation that women perceive and are perceived as "...passive objects of [male] desire." (Miers, 2000, p.36). Perhaps counter intuitively, feminism has been criticised for the polemical stance it has fostered in consideration of heterosexuality. Critics such as Segal (1997) have argued that promoting such polarised positions has served to make female sexuality even more invisible, with heterosexual relationships seen purely as a core social mechanism by which men continue to exert control and power over women. Hence, heterosexual women have remained silent about their own sexual desires and
expressions (Miers, 2000, p.204) and within patriarchal societies continue to experience dilemmas in responding to illness that affects both sexual function and femininity.

Social constructionist and feminist perspectives challenge accepted values in relation to the way biomedicine and nursing have traditionally viewed sexuality. Modern feminists have questioned the double standard whereby overt sexual expression is considered an integral aspect of masculinity, yet attracts social disapproval in women (Few, 1997; Segal, 1992). Criticism has also been levelled at writers who focus predominantly on the physical aspects of sexual behaviour, rather than encouraging its integration with the emotional and relationship contexts within which physical sensations are experienced (Segal, 1992; Few, 1997).

Much of the key empirical work by sexologists in the 1960s (Masters & Johnson, 1966) focused on sexual behaviour, particularly heterosexual intercourse, rather than the broader and more complex concept of sexuality. Such studies may be both narrow and reductionist in their perspective on human sexuality, and serve to reduce its expression to little more than a series of physiological responses (Lawler, 1991; Few, 1997). The language of sexuality, or at least of sexual expression, appears to be mechanistic, male-orientated and heterosexual, emphasising the powerful male phallus in pursuit of the passive, yet sexually responsive and available, female. Male sexuality tends to be represented as phallocentric and associated with power and performance more than its diffuse female counterpart. In contrast, female sexuality is often viewed predominantly in relation to women's reproductive capacities, such that women have become "...victims of their own reproductive anatomy." (Lawler, 1991:101). This perspective may emanate from earlier critiques of the origins of patriarchy whereby the "...universality of women's reproductive functions..." tie them "...to nature through their sexuality and fertility." (Turner, 1989:115). Thus gender representations bestow an inferior social status on women through their association with animality, nature and emotions as opposed to the superior (masculine) attributes considered to represent culture and rationality (Turner, 1989). Both religious ideology (Turner, 1989) and medicine (Weeks, 1992) have used their power and control in society not only to sustain, but at times to shape stereotypical views of female sexuality. These powerful social systems have perpetuated two diametrically opposed views of female sexuality, that of the "...passive, submissive, dependent receptacle of men's sexual drive..." and the "...tempting, seductive, insatiable woman who is a danger to men and is to be feared for her ability to overpower them with her wiles." Both are systemic examples of the ways in which traditional masculine definitions of sexuality may subjugate and misrepresent the sexual experiences of women (Bernhard & Dan, 1986:125).
Harding (1988) expressed concern about the ways in which these traditional constructions of sexuality specifically exclude the older woman. While the sexuality of the pre-menopausal woman is associated with her assumed capacity for biological reproduction, the concept of the post-menopausal woman becomes a medical problem. In recent decades the menopause itself has become medicalised, with the suggestion that women can remain *forever young* and fertile through the use of hormone replacement therapy (HRT) and new reproductive technologies. Harding (1988) argues that this sexist (medical) construction of post-menopausal women is antithetical to conventional femininity and sexuality, and thus excludes older women from dominant discourses on sexuality. One of the challenges in constructing an inclusive concept of sexuality for older women is that they are often single, having outlived their male partners. The conventional (*masculine*) definition of female sexuality is perpetuated if a woman’s behaviour can only be perceived as sexual in relation to her responsiveness to male sexuality (Harding, 1988). This gendered construction of female sexuality in later life is manifest through the ways in which older women who have never married are *pitied, as asexual spinsters left on the shelf*, while older single men, or *bachelors*, are assumed to have a sexual identity regardless of their age. These social meanings and associated use of language deny female sexuality a voice in older age, while at the same time they belie the work of both Kinsey (1953) and Masters and Johnson (1966) who confirmed that any lack of sexual activity in older women is more to do with lack of means (absence of a partner) rather than a lack of desire (Harding, 1988). Ultimately, separation of the concept of sexuality from its predominant association with a reproductive role may be important if sex and ageing (Allen, 1987), sex and the disabled (Chicano, 1989) disfigured, chronically ill (Hahn, 1989) or dying are to carry different social meanings for both health care professionals and society at large.

A recent feminist critique of cancer nursing literature on the subject of sexuality (Hyde, 2007) observed that the underlying theoretical perspective of biological determinism dominates much of both the nursing and sexology literature. She has argued that feminist scholarship and constructionist perspectives that acknowledge the socio-political context of sexual relationships are commonly omitted in mainstream cancer nursing and sexological publications. I would concur that the evidence base exploring female (and male) sexual morbidity associated with cancer treatment relies heavily upon a literature dominated by biomedicine. However, Hyde’s (2007) radical critique of literature said to privilege "...phallocentric heterosexuality over and above other forms of sexual expression....." and
one that fails to acknowledge the socio-political context of unequal gender power relations reinforces a polemical stance as opposed to advancing theoretical arguments on heteronormativity. While Hyde's (2007) argument may be important from a theoretical and research perspective, it offers little to develop the practice of cancer nurses who are challenged in providing even the most rudimentary sexual rehabilitation within traditional hierarchies of the cancer centre.

It could be argued that it is through the use of research methodologies that embrace feminist principles and engender greater socio-political awareness that a more appropriate and inclusive representation of the sexual health of women may be co-constructed.

2.4 Communication about Sexuality in Healthcare Contexts

In western secular cultures the ability to talk about sexuality and sexual behaviour in a way that conveys acceptance to the patient, and does not communicate an overtly negative or judgmental attitude towards an individual's sexual identity or their disclosure of particular sexual behaviours, is considered to be an essential pre-requisite for the assessment of sexual difficulties (Hawton 1985). The impact of negative attitudes on the provision of healthcare to patients from sexual minorities such as homosexual individuals or those who are transvestites or transsexuals may be the most obvious example where healthcare professionals express anxiety about being able to discuss sexual matters or seek to avoid caring for patients viewed as "sexually deviant" (Hayter, 1996). However, much debate continues as to whether or not negative or conservative attitudes towards sex and sexuality affect care delivery only when they are verbalised or acted upon directly as opposed to more subtle impacts such as the use of emotional distancing or avoidance behaviours by nurses (Hayter, 1996). It is therefore important to review literature that explores the nature of health professional's attitudes towards sexuality and the relationship of such attitudes with both practitioner knowledge about sexuality and, most importantly, with their observed practice and impact on patient care.

Early research exploring the knowledge, attitudes and anticipated behaviour of nurses regarding sexuality emanates from America with the work of Lief and Payne (1975) and Payne (1976). Lief and Payne (1975) compared the knowledge and attitudes towards sexuality of registered nurses, nursing students, medical students and college students not pursuing a course or career where sexuality would be an inherent aspect of their work.
The findings of this survey indicated that nursing students held more conservative attitudes towards sexuality than medical or other students, with registered nurses expressing the most conservative attitudes of all. The restrictive attitudes held by qualified nurses may have reflected the age difference and contrasting social climate that prevailed during their personal development compared to that of younger students.

A follow-up study by Payne (1976) used the Professional Sexual Role Inventory (PSRI) to measure how comfortable nurses were in addressing sexual issues arising from their professional role. The PSRI incorporated demographic factors known to influence attitudes to sexuality, namely the nurse's age, race, religious background and degree of religiosity, relationship status, place of employment (urban vs. non-urban) and educational background. Payne also used the Sex Knowledge and Attitude Test (SKAT) to evaluate the relationship between levels of knowledge held about sexuality and the nature of attitudes expressed towards that concept. The SKAT (developed by Lief, 1972) contains attitudinal items related to acceptability of masturbation, pre- and extra-marital sex, availability of abortion and specific sexual myths. This questionnaire survey achieved response rates of virtually 100% by administering the questionnaire to two contrasting groups of nurses (108 registered family planning nurses and 67 senior baccalaureate nursing students) attending study programmes at the same state university as the researcher. Three linked hypotheses were tested assuming a positive correlation between higher levels of knowledge about sexuality, the expression of a positive attitude towards sexuality and the greater comfort such nurses would have when faced with sexual issues encountered in professional role situations.

The results of Payne's (1976) study indicated that younger nurses (18-25 year old) and those who stated they were more religious had lower knowledge scores regarding sexuality, while married nurses and those from more urban employment settings tended to be both more knowledgeable about sexuality and to hold more liberal attitudes. There was no statistically significant relationship between level of education (degree versus non-degree education) and sexual knowledge scores when the age of the participant was taken into account. The trend for increased sexual knowledge scores among older participants can be accounted for by greater personal experience of sexual issues as well as increased educational opportunities. Despite sexuality representing a core element of their practice, the attitudes of family planning nurses were found to be the most conservative.
One of the limitations of this study was, however, that the PSRI used written patient care scenarios, with multiple choice answers, to evaluate the anticipated nursing response to a perceived need for information about sexuality. This methodology thus holds no predictive value in relation to actual practice behaviours that may be captured through direct observation of nurses in the practice setting.

Despite methodological and conceptual limitations inherent to attitudinal research, much of the nursing and healthcare research regarding sexuality from the 1970s and 1980s continued to focus on the link between knowledge and attitudes about sex. The assumption being that the more knowledgeable someone was regarding human sexuality, its expression and consequences, the greater the likelihood that they would hold a more positive or liberal attitude towards sexual issues integral to their professional practice. In 1988, Webb published a replication study of Payne’s (1976) research in the UK. She compared the knowledge and attitudes of a sample of 23 registered nurses working in two gynaecology settings with 27 nurses working in non-gynaecology settings. Her questionnaire survey failed to establish a clear link between increased knowledge and more liberal attitudes, casting doubt on the validity and reliability of the research instruments adopted by Leif and Payne (1975) and Payne (1976) 15 years previously. Webb’s critique of the SKAT highlights the cultural and historical context dependency of research instruments that attempt to measure complex, socially constructed concepts such as sexuality. Items deemed relevant for inclusion in an instrument developed in the 1970s in America, are likely to be based on a different set of values, knowledge and assumptions from those prevailing in the UK 15 years later; making their relevance to British attitudes and knowledge regarding sexuality in the 21st century largely irrelevant. Webb (1988) found that both groups of nurses in her study had low knowledge scores and traditional attitudes to sexuality, with gynaecology nurses even less knowledgeable and more conservative than the general medical / surgical nurses in her sample. Another interesting aspect of Webb’s findings was that while both groups in her study offered patient advice responses regarding physical aspects of sexuality, there were only five psychosocial items offered by respondents. Webb (1988) laments the fact that the nurses in her study appeared ill-equipped to discuss sexual issues with their patients. It is uncertain as to whether this was due to a lack of knowledge, a perception that sexual concerns were irrelevant to their role or that the nurses did not have the requisite social and communication skills to address such a sensitive topic.
The results of three early American studies within cancer nursing that of Fisher and Levin (1983), Williams et al. (1986) and Wilson and Williams (1988) found similar attitudinal and knowledge trends to research conducted in non-cancer settings. Fisher and Levin (1983) conducted a postal questionnaire survey among a sample of 145 qualified nurses working in oncology, achieving a response rate of 83%. The average age of respondents was 35 years, 45% of their sample were graduate nurses and the majority were female (96%). The results of this study were comparable with findings previously cited (Payne, 1976) namely that the mean knowledge scores (SKAT) were lower than that of a sample of graduate nurses tested in 1972 and attitudes more conservative for items related to masturbation, heterosexual relations and abortion using the research scales previously mentioned. These authors found a negative correlation between low knowledge scores, conservative attitudes and the extent to which participants reported active involvement in formal religion. They identified a positive correlation between the possession of higher educational qualifications, higher knowledge scores and the expression of more liberal attitudes towards sexuality. However, as the authors failed to modify any of the generic research instruments used, it is uncertain as to whether or not knowledge and attitudes specific to a cancer care context would have yielded different results.

In 1986 Williams et al. surveyed a convenience sample of 211 registered nurses attending a short cancer education programme (although only 26% of the sample subsequently proved to be currently working in oncology). In addition to their inclusion of research instruments containing specific items related to sexuality and cancer they incorporated two behavioural items claimed to represent nursing practice: the prevalence of teaching breast or testicular-self-examination and informing clients that they were available to discuss concerns regarding sexuality. Sixty seven per cent of respondents indicated they were comfortable talking to patients about sexuality, yet only 40 per cent of nurses felt they had a professional responsibility to do so. The majority of nurses in the study did not believe sexual counselling was part of their role and failed to teach breast or testicular self-examination. It could be argued that breast and testicular self-examination represents a cancer early detection strategy for a sexualised body part more than a true indicator of nurse’s ability to address the sexual concerns of their patients.

Wilson and William's (1988) study specifically explored the attitudes and practices that may influence the care of patients with cancer who have altered sexuality as a result
of their illness or treatment. They sent a postal questionnaire (Williams-Wilson Sexuality Survey: WWSS) to a random sample of 1500 registered nurses who were members of two American oncology nursing societies, including one specifically for paediatric oncology nurses, achieving a response rate of 62% (n = 937). Subsequent analysis was based on a total of 21 attitudinal items (Likert scales) and 12 behavioural items with interrater agreement of 92%. The items represented themes that included personal attitudes towards sexuality during illness, comfort in discussing sexuality with patients, beliefs about the success of intervention, sense of professional responsibility to address sexuality, patterns of referrals and communication about altered sexuality with both patients and other health professionals. The majority of respondents were females (97%) between the ages of 31 and 40 (43%) who had completed a bachelor’s degree (48%) as their initial educational preparation. Ninety per cent of nurses identified oncology as their area of speciality, 74% had between three and ten years of experience in oncology and 52% of respondents practiced within an acute in-patient setting.

The results of this study indicated the same attitude - behaviour disparity found in earlier studies. Ninety-one per cent of nurses agreed that sexuality should be a routine aspect of care for oncology nurses, with 92.4% of respondents stating they were comfortable discussing sexual issues when the patient initiated the topic and 57.9% of respondents comfortable initiating a discussion about sexuality themselves. However, this contrasted with behavioural indicators such as using the nursing diagnosis “Alteration in Sexuality” in routine care (32%), 89.5% of nurses reported they had offered sexual counselling to less than 10 of their patients in the past six months, 25% of nurses had never offered sexual counselling to their patients and 40% had never initiated a referral to a specialist resource.

There were a number of reported behaviours which, if they are an accurate indicator of actual practice, suggest an acceptable standard of care in relation to sexuality. For example, 82% of respondents reported they had discussed perceived loss of sexual attractiveness with patients and 64% stated they had continued this discussion with the patient’s partner. Factors that acted as a barrier to discussing sexual concerns in practice were lack of privacy, lack of knowledge, increased patient acuity, decreased length of patient stay and lack of access to specialist resources such as clinical nurse specialists to address such matters while ward nurses attended to “more basic needs” (Wilson & Williams, 1988).
In 1988 and 1992 two questionnaire surveys were conducted by Quinn-Krach & Van Hoozer in the USA and by Smook in the UK that explored nurse's knowledge and attitudes towards sexuality among older people, a client group of particular relevance to cancer care as the majority of those affected by cancer are older adults. Quinn-Krach and Van Hoozer's research sampled 158 American nursing students and findings demonstrated only a weak relationship between the variables of knowledge and attitudes towards sexuality. While the low response rate (29%) of Smook's (1992) study suggests caution in any interpretation of findings, this study also failed to establish any statistically significant relationship between knowledge and attitudes, suggesting that an increase in theoretical knowledge alone is unlikely to influence nurse's beliefs and values regarding sexuality in later life.

As can be seen from the studies presented thus far, a persistent theme in the research up until the early 1990s centred on manipulation of a knowledge-attitude relationship through the provision of nurse education specifically addressing the topic of sexuality. The assumption was that greater knowledge would lead to more liberal attitudes towards sexuality issues inherent to nursing practice and impact on subsequent care provision. Yet this assumption remains fundamentally flawed as social scientists continue to disagree on the nature of the attitude-behaviour link. Social scientists recognise that attitudes comprise cognitive, affective and behavioural elements. Several notable studies have called into question the assertion that attitudes are a principal determinant of subsequent behaviour towards an object (Berkowitz, 1986). Seminal work by La Piere (1934) is, despite methodological criticisms, frequently cited as the research which first alerted social scientists to the incongruence between expressed attitude and observed behaviour (cited in Fielding, 1986). Failure to establish the precise nature of the relationship between expressed attitudes and nursing actions perpetuates our limited understanding of how or whether an improvement in knowledge or attitudes towards sexuality would result in a change to actual nursing practice with the potential to translate into improved patient outcomes.

Although a growing body of evidence was emerging with regards to nurses' views towards discussing sexual concerns in healthcare practice, it was not until Waterhouse and Metcalf's (1991) study that the views of the general public were sought with regards to the appropriateness of sexual counselling by nurses. They found that 26% of respondents felt that nurses should 'always' or 'almost always' discuss sexual concerns with their patients,
with a further 66% believing that nurses should fulfil this role 'sometimes'. Attitudes were generally more positive among younger female respondents where sexual activity was deemed 'very or extremely important' to the person. Regrettably the validity and reliability of study findings was reduced by the unrepresentative nature of their sample (73 university employees of whom 73% were male, 96% Caucasian and 68% of whom held a bachelor's or higher degree) and the fact that attitudes towards nurses discussing sexual issues was measured using only one item from a 108 item questionnaire.

Waterhouse (1993) also collected data on the public's attitude towards doctors acting in the role of 'sexual counsellor' and found their responses were even more positive, with 66% of the sample stating that doctors should 'always or almost always' discuss sexual concerns with their patients and a further 34% reporting this should be the case 'sometimes'. No respondents felt doctors should rarely or never act in this capacity. These findings are in keeping with other studies comparing the public's views about nurses and doctors as an information resource in cancer care, with substantially more positive attitudes expressed towards doctors compared to nurses fulfilling this role. The preference for doctors in the role of information-giver appears to be consistent whether or not respondents are healthy subjects, as in Waterhouse's (1993) study or have had direct experience of nurses in such a role as is more likely to be the case in studies of patient populations (Meredith et al. 1996).

While previous studies tended to focus on nurses in discrete practice settings and specialities such as family planning (Payne, 1976), oncology (Wilson & Williams, 1988) or gynaecology (Webb, 1988), Matocha and Waterhouse (1993) conducted a study to explore the specific influence practice setting, among other variables, had on sexuality-related nursing practice. From a probability sample of 500 nurses registered in one American state, their postal survey achieved a response rate of 155 (31%) predominantly female Caucasian nurses. Although the majority held diploma or degree level qualifications, only 27% had received continuing education related to sexuality in practice. In addition to the evaluation of knowledge levels this study explored perceived comfort with the topic, personal and professional values towards sexuality and the nurse's practice setting was rated from one (low importance) to three (high importance) with regards to the extent to which the literature indicated that sexuality should be a "...frequent and essential focus of nursing care." (Matocha & Waterhouse, 1993, p.373). For example, intensive care and casualty scored lowest on this rating, oncology and gerontology were scored as
moderately important while areas such as gynaecology, mental and community health scored highest.

Their findings supported those reported previously, with the majority of respondents (71%) offering sexuality advice to less than 10% of their clients and only 31% of nurses stating they were "...very or extremely knowledgeable about sexuality." (Matocha & Waterhouse, 1993, p.374). This study found that practice area, place of employment, perceived knowledge level, perceived responsibility and comfort discussing sexuality were significant predictors (accounted for 41% of the variation in practice) of including sexuality as a component of practice. The only activities related to sexuality which were performed occasionally to frequently by the majority of nurses in the study were those initiated by clients and not nurses, including “listening to clients' concerns” and “answering questions about sexuality”. As with other studies reviewed, caution in interpretation of findings is necessary given both the small homogeneous sample and inevitable response bias.

Twenty years after its initial development (Lief 1972) a British study by Lewis and Bor (1994) used sections of the SKAT to establish sexual knowledge and attitudes of a sample of 357 registered nurses (50% response rate) in a major London teaching hospital. They found that the majority of registered nurses (78.5%) felt they were adequately educated with regard to sexual issues. Sixty-eight per cent had received some content in their pre-registration education although only 30 out of 160 had been helped to translate this knowledge into a useful clinical skill, that of being able to take a patient’s sexual history. Despite their positive perceptions regarding knowledge about sexuality, this sample of nurses achieved lower knowledge scores than Lief’s 1972 sample of graduate nurses (mean knowledge score of 34.96 compared to 39.13). While Lewis and Bor’s (1994) sample held more liberal attitudes towards heterosexual (pre- and extra-marital) sexual relations they held more conservative attitudes towards the availability of abortion.

Although theory represents a sound starting point there is a need for partnership with appropriate skills development to translate theoretical knowledge into practice change and improved patient experience. Support for skills development has to be consistent, accessible and be provided simultaneously in both educational and practice settings. Lewis and Bor’s (1994) findings demonstrate the complex relationships between personal and professional knowledge, attitudes, behaviour and emotions in determining the nature and scope of individual and collective practice. Nurses considered it was their role to provide sexual counselling (this constituted a patient teaching and support role as opposed to formal counselling) yet only 35% of the sample asked relevant questions regarding
sexuality during nursing assessment. The main reason given for this low level of practice appeared to be feelings of embarrassment (54% of respondents) that acted as a barrier to communication with patients.

Literature reviews and individual studies confirm that the majority of nurses recognise sexual health care as a component of nursing practice. However, specific patient education, support and counselling aimed at minimising effects of illness and treatment on sexual function is not provided by nurses the majority of the time (Gamel et al. 1993). One of the consistent reasons given by nurses to explain this apparent disparity between espoused care and actual practice is a perceived lack of knowledge about sexuality. While it would be unwise to say that specialist education has no impact on expressed attitudes or subsequent clinical practice, nursing interventions result from a complex interplay of the content, process and organisational culture of learning and practice in both the classroom and clinical settings (Waterhouse, 1996).

2.4.1 Sexuality as an uninvited guest in the health professional – patient relationship: professional perspectives

Recent studies have moved away from the specific measurement of attitudes towards sexuality and increasingly adopt methodologies that explore the diversity of individual, organisational and environmental factors that shape both patient and professional responses to the concept of sexuality. As mentioned previously (Matocha & Waterhouse, 1993) the profile and nursing awareness of sexuality as a priority element of practice varies with the clinical setting, patient diagnosis and type of treatments being offered. A scan of the literature reveals that discussing sexual issues poses a challenge in a variety of specialities, not only in oncology.

Guthrie (1999) adopted a grounded theory approach to explore the perceptions held by ten surgical nurses with regard to addressing sexuality within patient care. Qualitative analysis revealed three core themes emergent from the data: Talking, Stereotyping and Coping. Within the theme of Talking she found that nurses did not generally talk to patients about sexual concerns, expecting the initiation of such discussions to come from the patient. This expectation was accompanied by an assumption that patients would not want to discuss concerns about sexuality with nurses. Respondents expressed difficulty in discussing sexuality which they ascribed to a variety of factors including:

- Personal upbringing
• Prevailing social norms
• Status as staff nurses making them less accessible to patients due the burden of other responsibilities
• Constraints of time and privacy in the clinical environment
• Perception that sexuality was not a priority of care in their clinical setting

Guthrie (1999) addressed each of these ‘influences’ in turn and consideration was given to how many of these assertions were manifestations of avoidance and distancing tactics by nurses as opposed to legitimate barriers to discussion. In the theme Stereotyping further insight was gained regarding nurse’s perceived reluctance to discuss sexual issues with patients, that being the tendency for the media, general public and thus patients to stereotype nurses as sexual playthings. Wearing transparent white uniforms with their underwear on “Panty Parade” exposed the nurses to sexual harassment by male patients. Guthrie (1999) cited the work of Porter (1992) to explore the power differentials inherent in the nurse-patient encounter where sexual harassment could be interpreted as a mechanism by which patriarchal power relations were re-asserted by men who found themselves in a non-dominant and perhaps demeaning patient role.

2.4.2 Battleaxe, Angel or Whore? Implications of the sexual stereotyping of nurses

Sexual stereotyping, arguably, remains a detrimental and controlling process for both male and female nurses. While origins of the stereotype of the sexually permissive (female) nurse may be explored from a variety of perspectives (Porter, 1992; Lawler, 1991), a sociological analysis would suggest that this particular stereotype is a phenomenon of recent years (Kalisch and Kalisch, 1982 a,b,c). Prior to the 1960s, the media portrayal of nurses was predominantly that of "...chaste young women". However, the dawn of an era marked by sexual liberation led to female nurses being increasingly viewed as "...promiscuous playthings of their male medical colleagues." (Porter, 1992:521). His rationale as to why nurses are singled out, more than any other female occupational group, as the recipients of sexual innuendo, jokes and stereotyping relates to the fact that much of nursing work involves intimate physical contact with people’s bodies. Indeed, Fagin and Diers (1984) go further in proposing that as well as representing many other facets of the female role in a predominantly patriarchal society, nursing is also a metaphor for sex:
"...having seen and touched the bodies of strangers, nurses are perceived as willing and able sexual partners. Knowing and experienced they, unlike prostitutes, are thought to be safe: a quality suggested by the cleanliness of their white uniforms and their professional aplomb.”” (Fagin & Diers, 1984:17)

While one may question why stereotypes of the gay male or lesbian nurse have not been explored as extensively in the literature, popular social constructs of the nurse serve to simultaneously highlight and marginalise the concept of sexuality which is present in every human, social and therefore nursing action. The existence of lesbian nurses has yet to be articulated in mainstream nursing literature, reinforcing once more the apparent invisibility of female sexualities beyond the contextual boundaries of a masculine counterpart. Such mythology may serve to dissuade nurses from direct exploration of sexuality issues related to their patients. The desire to avoid confirmation of sexist or derogatory imagery relating to their professional role, or to their position as (predominantly) women in a wider society, may conspire to control this element of practice, through self and social surveillance.

The apparent invisibility of anything sexual within nursing was exemplified by Lawler (1991) herself, in omitting questions specifically related to sexuality from the interview schedule of her ethnographic study of the concept of the body and "body work" in nursing. It was only during her conduct of semi-structured interviews, when nurses spontaneously raised issues relating to sexuality and the body, that Lawler (1991) included sexuality as a central theme in her Foucauldian exploration of the concept of "embodied existence". Lawler (1991) offered an in-depth analysis of the problems created for an occupation such as nursing in its care of the "sexualised body". Despite the fact that repeated non-sexual touch is a fundamental aspect of nursing care, much of nursing work is heavily inscribed with sexual meaning. This often necessitates the creation of ritualised coping strategies whereby nurses make their work manageable through the reduction of both personal and patient embarrassment (Lawler, 1991).

Sexual harassment may be seen as a consequence of the prevalence of derogatory female sexual stereotypes in society, is encountered predominantly by women in the workplace and can lead to adverse emotional consequences as well as having a negative impact on the delivery of healthcare (Robbins et al. 1997). It is impossible to accurately estimate the prevalence of sexual harassment in nursing as such oppressive behaviour is seldom reported. In a UK questionnaire survey of qualified and student nurses by Finnis and Robbins (1994) 56% of nurses who completed the questionnaire...
(66% of registered and 35% of student nurse respondents) had experienced sexual harassment. Although patients were the most common perpetrators of this behaviour, male nursing staff and doctors were also increasingly implicated. While sexual harassment is experienced by individual practitioners, this abuse of male power is perpetuated by both a "...conspiracy of silence with the victim [and an] organizational collusion to inaction." (Robbins et al. 1997, p.166). Hence we can begin to appreciate the ways in which inclusion of sexuality in nursing practice is not simply determined by the interpersonal abilities and knowledge of individual practitioners but crucially by the extent to which sexual health care provision is supported by organizational culture and policy. Practitioners may remain reluctant to address the sexual well-being of their patients as long as they feel unsupported by service delivery models, management philosophy and environments that do not challenge the oppressive social context in which practice takes place and in which the sexuality inherent to body care and nursing remains unacknowledged (Lawler, 1991).

The final emergent theme from Guthrie's (1999) study was that of Coping, the strategies employed by nurses to cope with sexual issues arising in their work. Embarrassment was the most common emotion to prompt coping behaviours used by nurses in this study. Avoidance and distancing appeared to be the most commonly employed behavioural strategies reported by respondents, including the application of sanctions against patients who failed to behave in an acceptable manner. There was evidence that nurses minimised the impact of these situations and the feelings associated with them to what would then be viewed as a routine or daily occurrence that held no notable significance for them. Embarrassment in the nurse frequently occurred in response to their perception that the patient was embarrassed, with both nurses and patients using humour to cope with situations that provoked such feelings. The management of embarrassment is an important element in communication about sexuality from both a patient and professional perspective. Embarrassment is noted as a frequently occurring barrier to communication about topics deemed to be sensitive and situated in an individual's private as opposed to public life domain. This may be considered to occur particularly when expected social norms and conventions are either deliberately or unwittingly breached. Both Lawler (1991) and Meerabeau (1999) explored the manifestation and management of embarrassment in healthcare practice. Lawler's (1991) grounded theory study of nursing work and body care explored how nurses defined and managed their embarrassment and that of the patients for whom they provided intimate
body care. Embarrassment was defined as an interpersonal and social process by which this uncomfortable psychological state occurs as a result of having knowingly but not deliberately broken or failed to observe a set of social rules in front of an audience (Lawler, 1991, p.137). Lawler noted a number of ways in which, through experience, nurses learned to manage the embarrassment encountered in doing body work. Nurses used speed to minimise the time they would be exposed to particular situations and adopted a fatalistic stance about certain tasks, thus defining some unpalatable situations as unavoidable. They created a shared understanding with colleagues by exchanging practice narratives that promoted a collective view of embarrassment that was inherent to aspects of their [body] work as opposed to a personal failing. There were a number of circumstances whereby the inherent sexuality of the nurse and/or patient created embarrassment through breaking social rules. For example, where patients did not behave modestly in covering their bodies, or engaged in sexually suggestive or explicit behaviour. Such behaviour broke the social rule of patients experiencing some (albeit not excessive) embarrassment during body care. Sexually explicit behaviour and interpreting a situation as sexual when this was not the case were constituted by nurses as forms of sexual harassment (Lawler, 1991). As so much of what nurses do is intimately connected to the body, a body that is "...heavily inscribed with sexual meaning..." a number of strategies were adopted to manage such encounters (Lawler, 1991, p.152). Lawler (1991, p.151) identified five contextual elements that defined a nurse-patient encounter as nursing as opposed to sexual. These were:

- The nurse's uniform: its symbolic meaning, e.g. clinical, formal, impersonal
- The nurse's manner: 'being professional', 'being matter-of-fact'
- 'Minifisms': verbal and/or behavioural strategies which served to minimise the significance/importance of a problematic situation in order to make it more manageable, e.g. "Vaginal examinations don't bother me, I've seen so many of them."
- Creating privacy: e.g. asking patient's visitors to leave
- Discourse privatisations: private discussion of bodily functions between nurse and patient where there is lowering of the voice and spatial isolation to create privacy, e.g. use of screens

Drawing on a synthesis of existing literature and empirical data emanating from observational research in fertility clinics, Meerabeau (1999) traced the evolution of
embarrassment from its origins as fear of physical attack in exposed or vulnerable social situations to the feelings of shame and embarrassment experienced in more developed societies. People living in industrialised societies have become accustomed to greater privacy and expect containment and concealment of bodily functions as the norm. Embarrassment as an emotional reaction, together with its physical and behavioural manifestations, is more commonly associated with social situations where a "...central assumption in a transaction has been unexpectedly discredited for at least one participant..." (Meerabeau, 1999, p.1507). The ability to manage embarrassment through strategies such as avoidance, minimisation or humour and to be able to repair any perceived damage to reputation and poise, are essential elements of early socialisation processes for any individual (Meerabeau, 1999) but perhaps even more important for nurses. Meerabeau's (1999) observation of fertility clinics highlighted a significant discrepancy between espoused beliefs about the importance of including discussions about sexual competency in couple evaluation and actual practice, with only six out of 160 observed consultations incorporating any direct questioning or discussion of the couple's sexual relationship. Patient or health professional embarrassment as a reason for limited discussion of sexual concerns in clinical practice is cited by the majority of studies reviewed, but has only been explored in detail within the research of Lawler (1991) and Meerabeau (1999).

Cort et al. (2001) conducted a questionnaire survey of 122 community mental health nurses whose role included supporting patients where illness and medication frequently disrupt relationships and sexual expression. Findings were comparable with other studies reviewed, for example while nurses viewed sexuality as a legitimate focus of health care they remained ambivalent about actively broaching the subject with patients due to embarrassment, lack of knowledge, time constraints and fear of offending or causing distress to the patient that would ultimately disrupt the professional relationship. Practitioners were supportive of clients with mental health problems having intimate relationships (62.3%, n = 76) and 63.1% of respondents anticipated that sexual difficulties were likely to occur in this client population. However, despite this perceived need for client assessment and support regarding sexual well-being, only 52.4% (n = 64) agreed that a sexual history should form part of their nursing assessment, again underlining the divergence between practitioner attitudes about sexuality and actual practice. Some
practitioners were reticent to conduct a sexual assessment in the client's own home where there may be safety concerns for community staff (Cort et al. 2001).

Although much of the literature to date has focused predominantly on nurses, other health professionals find discussion of sexuality equally challenging. In the 1980-1990s, with the emergence of AIDS and HIV infection as a substantial threat to public sexual health in both developed and developing countries, a number of studies endeavoured to explore why doctors were reluctant to take a sexual history as part of patient evaluation. An American survey (110 Likert statements) of 350 senior medical students by Merrill et al. (1990) revealed the same attitude-practice gap as found in the studies of nurses, namely that while 93% of them believed in the importance of sexual history taking, only 50% of them believed they had been adequately trained to carry out such an assessment and 25% were too embarrassed to ask the questions necessary to elicit such information. Additional Likert scales measuring shyness and social anxiety were also used to identify if the reluctance and embarrassment expressed by some students was related to particular personality traits. Merrill et al. (1990) found that embarrassment in taking a sexual history was correlated with a high score on the shyness-social anxiety scale (r = 0.50, p<0.01). Students who held the belief that a sexual history was not relevant to a patient's medical condition, or was considered unimportant, correlated strongly with a negative orientation to psychological problems / difficulties in practice (r = 0.054, p<0.01). They also found that students who felt adequately trained to undertake a sexual history were more likely to score high on self-esteem (r = 0.36, p<0.01) and low on shyness-social anxiety (r = -0.23, p<0.01). These findings suggest that while personality, beliefs and values regarding sexual behaviour are relevant to practitioner's confidence in discussing sexual concerns within the context of potential AIDS / HIV infection, appropriate targeted education and role modelling can have a positive moderating effect on practice beliefs and knowledge. However, there is still uncertainty regarding whether or not this translates into less prejudicial attitudes and a decrease in avoidant behaviour in practice.

A more recent American postal survey (n = 131) of sexual history taking by physicians sampled qualified obstetricians, gynaecologists, family doctors, paediatricians and surgeons. Burd et al. (2006) reported that 88% (n = 40 male and 29 female physicians) of respondents took sexual histories. However, despite the relatively good level of history taking in this small heterogeneous sample of doctors there was an interesting pattern of physician discomfort associated with opposite gender consultations.
Burd et al. (2006) found that 19% of male physicians reported discomfort talking to male patients compared to 50% of female physicians. This compared to 35% of male physicians and 12% of female physicians reporting discomfort when discussing sexual issues with female patients. When physicians of each gender were asked to consider whether or not patients of different gender felt uncomfortable in discussing sexual matters with them, they reported that 40% of male and 45% of female doctors perceived male patients were uncomfortable discussing sexual matters compared to 53% of male and 24% of female doctors who thought female patients found such discussions uncomfortable. Although there was no evidence from the study data that such perceptions adversely affected the rate of sexual history taking or the elucidation of sexual dysfunction by doctors, these findings suggest that physicians feel more comfortable and perceive their patients to be more comfortable when discussions are between the same genders.

Other factors that doctors felt created discomfort when discussing sexual issues with patients were the patient's age (patients younger than 18 and older than 60 years), those with a lower level of education and patients without a current sexual partner. It was particularly interesting to note that 44% of this sample of doctors (97% of whom categorised themselves as heterosexual) perceived that sexual history taking caused discomfort for homosexual patients. This percentage falls within the range of results obtained when doctors were asked to consider the perceived comfort of opposite gender consultations where sexual orientation was not considered. Perhaps heteronormativity was assumed and so it is difficult to know whether the sexual orientation of patients is an additional factor creating perceived discomfort for the doctor and patient or not (Burd et al. 2006).

One of the few studies that focused on the structure and organisation of talk in medical consultations used elements of conversation analysis to illustrate how discussion of sexual concerns differs from other aspects of gynaecological consultations (Weijts et al. 1993). Analysis of naturally occurring talk within gynaecology consultations revealed that women and their doctors (all male) co-constructed the topic of sexuality as a “delicate” matter requiring what was referred to as “expressive caution” in the use of language. Thirty-two consultations involving five male gynaecologists (aged from 37-50 years) and 15 individual women (aged from 18-49 years) were taped and transcribed verbatim before being subjected to conversation analysis. Scrutiny of the transcripts as a complete set of data revealed that almost half of the women mentioned sexual difficulties after first having offered other gynaecological complaints. Furthermore, when sexual issues were raised the
language in the consultation appeared to alter drastically and represented what was
termed as delicate talk. Delicate talk was characterised by a number of linguistic strategies
on the part of both the patient and the doctor. The topic of sexuality was often delayed in
its disclosure until towards the end of a consultation or full discussion delayed by the
gynaecologist to a subsequent consultation where it was then not addressed. Delay was
also evident through excessive speech hesitations or pauses immediately before selecting
a word relating to a sexual issue or delays in answering direct questions from the doctor
about sexuality.

The analysis also revealed a tendency for doctors to use leading questions when
asking about sexual concerns, thus displaying ideas of what was considered 'normal' in
those circumstances. Such a strategy either acted as a barrier to honest responses when
the woman’s experience differed from the projected norm or made her response easier
because she could rationalise her disclosure of a sexual concern as being at the request
of her doctor rather than something for which she retained responsibility.

Where a woman hesitated excessively in responding to a direct question about sex the
doctor was seen finishing the sentence for the patient by producing the delicate term, thus
saving face for the patient and reinforcing their role as the professional expert.

Weijts et al. (1993) also noted avoidance in the use of sexual language through the choice
of vague terms such as ‘down there’ or simply omitting direct reference to sex completely,
leaving the doctor to draw his own conclusions through the provision of adequate context.
Other linguistic devices included the use of pronouns such as ‘it’ or ‘afterwards’ to denote
sexual intercourse and depersonalisation such as referring to ‘the’ as opposed to ‘your’
vagina or ‘the penetration’ and ‘the event itself’ to replace ‘when you’re having intercourse’.
Such language may reduce embarrassment by creating an opportunity to talk in a more
abstract and impersonal manner about a very personal aspect of a woman’s life. However,
while such linguistic strategies and co-construction of female sexuality may reduce
embarrassment for both actors in the social exchange, myths and misunderstandings
about the nature of the sexual difficulty may go unchallenged due to the superficial nature
of the resulting conversation.

In a recent British study by Gott et al. (2004a) 22 GPs (34% response rate) were
interviewed in-depth to ascertain their perceptions of the management of sexual health
issues in later life. A grounded theory analysis revealed that the dominant view of sexual
health espoused by these doctors tended to equate with issues encountered in a younger
patient group, namely those linked to prevention of teenage pregnancy and spread of sexually transmitted infections. GPs appeared to split into two clear groups: those who adopted a proactive role in sexual health management, initiating discussions with patients when deemed appropriate versus those who saw their role as more reactive, only responding to sexual issues when they were raised by patients. Even among the GPs who considered themselves "proactive", there was recognition that they were less likely to adopt such a stance with their older patients. Ageist assumptions about the likelihood that older patients would still be sexually active appeared to shape the content of consultations where sexual issues could be raised. GPs reported experiencing surprise on the infrequent occasions when an older patient initiated discussion of sexual concerns. Those deemed older could be aged anywhere from 40-80 years, dependent on the specific focus of the anticipated discussion e.g. "safe sex" as opposed to erectile dysfunction (ED) caused by diabetes or heart disease. However, despite the somewhat narrow definition of sexual health adopted by the GPs in this study, a number of them recognised the important 'permission giving' role they fulfilled in supporting older patients to maintain sexual activity despite the effects of ageing on function or relationship breakdown associated with divorce or bereavement.

As found in other studies, doctors often used the discussion of contraceptive advice or reproductive health as a vehicle for discussion of broader sexual health matters and when this option was no longer available to them, for example in post-menopausal women, there was a reduction in sexual health discussion accordingly (Gott et al. 2004a). Reluctance to discuss sexual issues with older patients was shaped by the concern that they would cause offence in raising a topic older people tend to view as private or illegitimate within a health care context together with responding to ageist stereotypes as opposed to the reality of older people's lives and relationships (Gott et al. 2004a). Data taken from the same study and reported elsewhere included findings emanating from interviews with 35 practice nurses and identified a number of barriers to sexual health discussions in the primary care setting including the perceived sensitivity and complexity of the topic, constraints of time and expertise in this clinical setting and particular anxiety about discussing sexual concerns with patients of the opposite gender and those from cultural, religious or sexual minorities (Gott et al. 2004b).

Few studies explore the discussion of patient's sexual concerns by other members of the health care team. In the field of disability and rehabilitation one study by Haboubi and
Lincoln (2003) found that occupational therapists and physiotherapists had the least training, were most uncomfortable and least willing to have discussions with their patients about sexual concerns (p<0.001). Consistent with other studies reviewed, while 90% of the total number of respondents (n = 813) agreed that addressing sexual issues should form part of holistic care, only 6% were likely to initiate discussion regarding sexual concerns on a frequent basis. Eighty-six per cent of the staff surveyed were found to be poorly trained in this aspect of rehabilitation practice.

These results indicate a greater theory-practice gap than that found in studies of doctors and nurses and may reflect the particularly poor provision of specialist continuing education for paramedical staff compared to that of their medical and nursing colleagues. Doctors raised the topic of sexuality with their patients more than any other professional group and were less likely to be adversely affected by lack of training (p<0.001) or embarrassment (p<0.002). Overall, 68% of respondents never initiated a discussion of sexual concerns, preferring to wait for patients to do so. Female practitioners were more likely to experience embarrassment (p<0.001) and to perceive that their comfort in discussing sexual issues would be improved through training (p = 0.01). As with other studies reviewed in this chapter the perceived barriers to discussing sexual issues were lack of training (79%), time constraints (67%) and practitioner embarrassment (50%). Barriers emanating from patient characteristics were identified as the patient’s age (61%), physical well-being (54%), gender (52%) and relationship status / stability (42%). A surprising finding from this study was that practitioners working within medical wards were more likely to discuss sexual issues with patients than those based in a rehabilitation unit, thus challenging the assumption that a patient's sexual recovery might be better managed within rehabilitation settings (Haboubi & Lincoln, 2003).

In exploring health professionals' views about discussing patients' sexual concerns it is clear that a number of inhibitory factors continue to affect staff’s perceived comfort and competence regardless of the practice setting or disciplinary background. However, as health professionals are only one part of this communication process the next section offers some insights from a patient’s perspective.

2.4.3 Sexuality as an uninvited guest in the health professional – patient relationship: patient perspectives

The literature suggests that women may be more reluctant to discuss sexual concerns than men, regardless of who they choose to approach within the health care system.
In a qualitative study by Sarkadi and Rosenqvist (2001) 33 women aged 44 - 80 yrs were asked about their willingness to discuss sexual concerns with general practitioners (GPs). Findings suggest that many women considered their doctor's personal characteristics before reaching a decision to consult them about a sexual concern. Many expressed a preference to see a female gynaecologist of a similar age to them and to be given the time and privacy for such a discussion. Some felt their doctor was too shy to be able to discuss sex with them while others felt that if their GP was the person they saw regularly for their diabetes management, they could not conceive them in the role of “sexual counsellor”.

Recent qualitative studies of GPs and older people's attitudes to discussing sexual issues in primary care (Gott & Hinchliff, 2003; Gott et al. 2004a) offer useful insights into the diverse factors affecting communication with an older age group (55 - >70 yrs) from both patient and health professional perspectives. Gott and Hinchliff (2003) conducted semi-structured interviews with 22 women and 23 men (50-92 years of age) and found that 25 of their sample had a current or recent sexual problem, yet only six of the participants had sought help for their difficulties. Participants identified the GP as their preferred source of professional help but it became clear that this was at least in part because they were unaware of any alternative sources of sexual health services. The barriers to seeking help cited by older people were diverse and included:

- The personal characteristics of the GP (age, gender)
- GP attitudes towards sexuality in later life
- Attribution of sexual difficulties to part of ‘normal ageing’
- Shame / embarrassment or fear
- Perceiving sexual problems as ‘not serious’
- Lack of knowledge of appropriate services regarding sexual health

Gott and Hinchliff (2003) noted that older patients rarely initiated discussions about sexual concerns themselves. They expressed a preference for GPs with similar personal characteristics and hence perceived similar experiences to them in order to minimise the embarrassment associated with discussing sexual issues. Older people saw sex as a private issue that should be “...kept quiet...live with it instead of seeking some sort of help.” (Gott & Hinchliff, 2003, p.693).

In a grounded theory study conducted with women treated for ovarian cancer from eight to 120 months previously (Stead et al. 2001), it was clear that most of them wanted written
information or discussion about sexual issues from their treatment team. Of the women interviewed (n = 15) none had received written information and only two had brief verbal information from their doctor. While some of the women expressed discomfort at the thought of discussing sexual issues, they felt that the personal benefits of doing so would outweigh any embarrassment they experienced. They also acknowledged that in a time-pressured environment they would be satisfied with brief factual information that conveyed permission to raise the topic, and to be offered reassurance that they were not unique in the fears and concerns they held (Stead et al. 2001).

While there is some evidence of women's reluctance to discuss sexual concerns in a clinical context, earlier work by the same principal author (Stead et al. 1999) demonstrated that women did not find appropriately worded questionnaires about their sexual function intrusive in the context of a clinical trial. Compliance rates in excess of 80% were achieved among a mixed sample of women with advanced ovarian cancer (n = 96) and women undergoing different types of hysterectomy for benign disorders (n = 542). Furthermore, willingness to complete the questionnaire was not adversely affected by the age of the woman or her current level of sexual functioning. Both trials used the Sexual Activity Questionnaire (SAQ) in the long term (six weeks to 24 months following randomisation) evaluation of treatment impact on women's sexual functioning. Interestingly this instrument was originally developed to elicit the sexual impact of long term tamoxifen (an anti-oestrogen compound) use in chemoprevention trials of healthy women at high risk of breast cancer. The rationale for the development of the SAQ was that existing instruments "...which are designed specifically to investigate primary sexual dysfunction are often unnecessarily explicit." (Stead et al. 1999:51). The SAQ is a self-report questionnaire comprising three sections that address the hormone status of the woman, her relationship status, reasons for sexual inactivity (where applicable), and levels of sexual functioning. This latter section is subdivided into items addressing pleasure from sexual intercourse, discomfort during intercourse, and how "usual" the reported behaviour was to the woman and her partner. Of the 70 women with advanced ovarian cancer (age range 33-76 years) who completed the questionnaire at baseline, 49 (70%) were in an intimate relationship, 22 (45%) were currently sexually active. This compares with 454 women (age range 24-74 years) in the hysterectomy trial who completed the baseline questionnaire, 91% of whom were in an intimate relationship and 83% who were currently sexually active.
Eight of the women with ovarian cancer found the SAQ questionnaire "intrusive" at baseline, although four of them still completed the assessment. Many of the women provided additional comments that suggested they found the SAQ thorough without it being too personal or embarrassing. Overall, women appeared willing to provide intimate details about themselves and their partner regarding current sexual difficulties.

Regardless as to whether one explores the barriers to discussing sexual concerns within healthcare practice from a professional or patient perspective, what is intriguing is the extent to which published research fails to explore the reasons given for such reluctance in any depth. There is also inadequate exploration of the organisational and social factors that influence the ways professionals, patients and partners socially construct their meanings about sexuality both collectively and individually. Patients and health professionals each carry their individual frames of reference when it comes to sexual identity, sexual orientation and sexual expression. Research from sexual health, psychosexual medicine and therapy has identified a number of factors that shape an individual's personal views about sex. These factors inevitably influence their comfort or discomfort in discussing what many consider a private subject, even with their spouse or partner. While we may hold specific views about sexual expression and sexuality in the context of our own lives, it may be more challenging to view the sexuality of others through the lens of illness, disability, disfigurement, incontinence or simply old age.

Recent research in healthcare and cancer practice suggests that there is an increased awareness about sexuality as manifest in broad acceptance of the need to discuss the sexual consequences of cancer and its treatment with patients. Where there is still considerable work to be done is in the translation of that awareness into nursing and medical action (Stead et al. 2003).

Taboos about sexuality and cancer still remain, leading us to research some groups of patients extensively and to neglect others, even when treatment toxicity can cause similar sexual difficulties. In a literature review that included published English language papers in cancer care from 1999 to 2004 inclusive, 263 relevant sources were identified that addressed sexuality in cancer to a greater or lesser extent (White, 2005). While there were a number of papers that focused on cancers affecting the breast and male or female genitalia, comparatively few studies explored the sexual consequences of treating anal or rectal cancer. This disparity is explored more fully through critical appraisal of the biomedical literature in the subsequent sections of this chapter.
2.5 The Sexual Consequences of Pelvic Radiotherapy in Combined Modality Treatment for Cervical or Endometrial Cancer

As survival rates in the developed world for cervical and endometrial cancer continue to improve, both health practitioners and women affected by these illnesses have begun to focus increasingly on the quality of that survival (Vistad, Fossa & Dahl, 2006). Treatment has evolved to include a multi-modal approach to manage these cancers and only those with early stage disease and good prognostic factors now avoid combined therapies. Women with locally advanced cancers or those where there are poor prognostic indicators are increasingly receiving external beam radiation and brachytherapy or chemo-radiation (Vistad, Fossa & Dahl, 2006). Inevitably, while survival rates often improve as a result of multi-modal treatment regimens, this is not without an associated increase in both acute and late treatment related toxicity.

The sexual impact of multi-modal cancer therapy is normally considered a treatment late effect as pathophysiological changes in the organs and tissues within the pelvis, particularly those associated with radiotherapy, may continue to develop for up to two years post completion of treatment. It is these changes that account for the physical effects and associated psychological responses (see Table 2.1) that impact negatively on the sexual health of women and their partners (Andersen et al. 1989; Schover et al. 1989; Bruner et al. 1993; Cull et al. 1993; Flay & Mathews 1995; Bergmark et al. 1999; Juraskova et al. 2003, Davidson et al. 2003a; Jensen et al. 2003). Sexual difficulties following treatment for gynaecological malignancy have received increased attention in recent years, with studies reporting prevalence rates ranging from 50-80% among women who received pelvic radiotherapy for cervical cancer (Crowther et al. 1994; Flay & Mathews 1995).

These findings are supported by more recent quality of life (QOL) and radiotherapy morbidity studies where women receiving primary or adjuvant pelvic radiotherapy experienced greater and more prolonged disruption to their sexual well being (Jensen et al. 2003; Davidson et al. 2003a) than women after surgery alone (Leake et al. 2001; Juraskova et al. 2003). QOL studies also highlight the multifactorial and complex nature of female sexuality during recovery from cancer (Leake et al. 2001; Tabano et al. 2002; Juraskova et al. 2003). This complexity has only recently begun to be explored in
radiotherapy morbidity research (Davidson et al. 2003a; Davidson et al. 2003b; Jensen et al. 2003).

Table 2.1: Summary of Factors Contributing to Sexual Difficulties in Women Receiving Pelvic Radiotherapy

<table>
<thead>
<tr>
<th>Physical Factors</th>
<th>Psychological Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaginal dryness</td>
<td>Fear of sex causing cancer recurrence</td>
</tr>
<tr>
<td>Vaginal stenosis or shortening</td>
<td>Fear of transmitting cancer to partner via sexual contact</td>
</tr>
<tr>
<td>Vaginal bleeding &amp; discharge</td>
<td>Fear of contaminating partner with radioactivity</td>
</tr>
<tr>
<td>Vulvovaginitis</td>
<td>Fear of sexual pain</td>
</tr>
<tr>
<td>Menopausal symptoms</td>
<td>Anxiety</td>
</tr>
<tr>
<td>Perineal skin reactions</td>
<td>Depression</td>
</tr>
<tr>
<td>Cystitis</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Proctitis</td>
<td>Altered Self-concept / Femininity</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>Poor couple communication</td>
</tr>
<tr>
<td>Infertility</td>
<td>Woman &amp; partner coping styles</td>
</tr>
</tbody>
</table>

Clinical oncologists recognise the difficulties in achieving accurate treatment toxicity evaluation due to inadequate recording of radiotherapy morbidity both within research and, more importantly, routine clinical practice (Davidson et al. 2002; Davidson et al. 2003ab; Saunders 2003). There is significant under reporting of radiotherapy morbidity due to the length and complexity of research tools available (Davidson et al. 2002; Davidson et al. 2003ab). Consequently, understanding the specific impact of radiotherapy late effects upon an individual’s well being remains incomplete (Faithfull 2004; Davidson et al. 2003a).

A recent critical review of patient-rated QOL studies in women who are long-term survivors of cervical cancer provides an invaluable synthesis of the research evidence to date as there is a plethora of studies in this patient group (Vistad, Fossa & Dahl, 2006). These authors used both methodological and treatment-related criteria to provide a quality score for the existing empirical evidence base and identified areas in need of further research. Of the 516 papers published from 1966-2005, only 23 studies met all of their inclusion criteria. Quality criteria were applied to each of the papers although the review included studies with obvious methodological weaknesses in order to identify those likely to yield the most relevant and valuable information for the management of this group of women. The quality rating scale was devised based on internal validity and treatment-related factors.

Vistad, Fossa & Dahl’s review (2006) identified the most common domains of quality of life covered by the studies including physical well-being and symptoms, psychosocial status and sexuality. They also conducted a quality appraisal of the QOL measures used in the
studies. For the purpose of this literature review only the data relating to the domain of sexuality and associated measures of sexual functioning will be discussed in detail. However, it is worthy of note that Vistad, Fossa & Dahl's (2006) review established the important contribution of associated aspects of physical (bowel and bladder toxicity, fatigue) and psychosocial (anxiety, depression, fear of recurrence) well-being to overall perceptions of QOL and inevitably to perceptions of sexual well-being. In many ways one of the criticisms of QOL research relates to the false divisions which are made in exploring different QOL domains and presenting findings as if there is no interaction or compounding effect made by, for example, changes in bowel or urinary function on sexual well-being. What women experience is a complex cluster of inter-related and interacting symptoms which collectively impact on their recovery post-treatment to varying degrees. This point is particularly important in considering female sexuality which appears to be highly responsive to changes in the psychosocial elements of a woman's life (Willert & Semans, 2000). Not only might one expect depression or anxiety to have an impact on sexual interest, but generalised worry or preoccupation with fear of disease recurrence and fertility concerns are also likely to adversely affect sexual well-being (Schover, 1997).

This critical review identified a total of 12 studies which had specifically explored the impact of cervical cancer and its treatment on sexual well-being, 10 of which included women treated by pelvic radiotherapy alone or combined with other modalities. They found that reduced vaginal lubrication was the most common difficulty reported in the studies reviewed when compared to a normal population of women. Vaginal dryness was also frequently reported in the studies deemed to be of lesser methodological rigour. Findings were conflicting with regards to whether surgery or radiotherapy was the principal modality responsible for this symptom (Vistad, Fossa & Dahl, 2006).

While Bergmark et al. (1999) did not detect any modality related difference in the prevalence of post-treatment dyspareunia or vaginal stenosis, studies by Jensen et al. (2003) and Schover et al. (1989) found a significantly higher prevalence of vaginal problems after radiotherapy compared to surgical treatment alone. The review found that the frequency of sexual expression post-treatment was generally less than that retrospectively reported as the woman's pre-treatment norm (Vistad, Fossa & Dahl, 2006). When compared with women of a similar age from the general population, or with women who were treated by surgery alone, both Jensen et al. (2003) and Schover et al. (1989) found increased levels of superficial and deep dyspareunia (55% and 21% respectively) at 12 months post-treatment. Women who had received radiotherapy were also more likely to
report post-coital bleeding (Schover et al. 1989) and 29% and 45% of women respectively considered development of a “short vagina” as problematic (Bergmark et al. 1999; Jensen et al. 2003).

Jensen et al. (2003) found that women who had received radiotherapy had reduced levels of sexual interest at two years post-treatment compared to age matched controls, although Bergmark et al. (1999) and Wenzel et al. (2005) observed no such difference in women assessed at five years post-treatment. There was no obvious reason for the discrepancy in these study findings. While Wenzel et al. (2005) had a smaller sample size (n=51), all three studies used control groups, duration of follow-up was adequate ranging from 24->60 months and all three studies were quality rated as demonstrating good methodological rigour (Vistad, Fossa & Dahl, 2006).

In the 19 radiotherapy studies where post-treatment sexual function was evaluated, researchers had used a total of 10 different research instruments (see Table 2.2) the majority of which had not been tested for validity and reliability in women treated for cervical cancer.

Table 2.2: Research Instruments to Evaluate Sexual Dimensions of QOL in studies of women post-radiotherapy for cervical cancer

<table>
<thead>
<tr>
<th>Author</th>
<th>Research Measure</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bergmark et al. (1999)</td>
<td>Self-made</td>
<td>Not validated</td>
</tr>
<tr>
<td>Jensen et al. (2003)</td>
<td>Sexual Function-Vaginal Changes Questionnaire (SVQ)</td>
<td>Reliability &amp; Validity Established 20 items Dimension-specific</td>
</tr>
<tr>
<td>Schover et al. (1989)</td>
<td>Self-made</td>
<td>Not validated</td>
</tr>
<tr>
<td>Wenzel et al. (2005)</td>
<td>Sexual Activity Questionnaire (SAQ)</td>
<td>Reliability &amp; Validity Established 21 items Dimension-specific</td>
</tr>
<tr>
<td>Butler-Manuel et al. (1999)</td>
<td>Self-made</td>
<td>Not validated</td>
</tr>
<tr>
<td>Cull et al. (1993)</td>
<td>Rotterdam Symptom Checklist (RSCL)</td>
<td>Reliability &amp; Validity Established 34 items (physical &amp; psychosocial dimensions) Disease-specific</td>
</tr>
<tr>
<td>Davidson et al. (2003)</td>
<td>LENT-SOMA</td>
<td>Reliability &amp; Validity compares with other RT late effect scoring systems 37 items (physical dimensions) Disease-specific</td>
</tr>
<tr>
<td>Krumm &amp; Lamberti (1993)</td>
<td>Self-made</td>
<td>Not validated</td>
</tr>
<tr>
<td>Lalos &amp; Lalos (1996)</td>
<td>Self-made</td>
<td>Not validated</td>
</tr>
<tr>
<td>Lasnik &amp; Tatra (1986)</td>
<td>Self-made</td>
<td>German language Not validated</td>
</tr>
</tbody>
</table>
In table 2.2 the studies in bold type achieved a methodological rigour quality score of 10 or greater in Vistad, Fossa & Dahl's (2006) critical review. Only four of the 10 studies were deemed to have achieved good methodological rigour. Four of the 23 studies reviewed focused on women who were treated by surgery alone and have not been discussed here. Of the 19 QOL studies that included samples of women who had received pelvic radiotherapy alone or in combination with other treatment modalities (surgery and / or chemotherapy) seven were deemed to exhibit good methodological rigour (quality score of 10 or greater) while 12 were considered to have methodological weaknesses that should lead to a more cautious interpretation of their findings. An interesting finding given the trend towards multi-modal treatment for most types of pelvic malignancy was that women receiving single therapy reported significantly higher quality of life compared to women receiving multimodal treatment regimens. Women with early stage cervical cancer and those treated by surgery alone had a quality of life similar to an age-matched general female population (Vistad, Fossa & Dahl, 2006).

The diversity of research instruments used, together with the number that were not validated makes it difficult to compare findings across studies and reach a convincing synthesis of results. Many of the studies used a retrospective design, leading to the possibility of selective recall bias, and the majority of studies failed to take adequate account of confounding variables such as age, education level, relationship status, stage of disease, treatment modality, use of hormone replacement therapy (HRT) or time elapsed since diagnosis.

Some studies appeared to suggest that deterioration in sexual function may be deemed by women as an acceptable cost for surviving a serious illness such as cancer. This assumption was based on the number of studies which were unable to show any reduction in global measures of quality of life (QOL) when compared to healthy age-matched controls despite substantial disruption being present in relation to women's sexual expression and well-being following cancer treatment. Vistad, Fossa & Dahl (2006) explored this phenomenon of response shift in QOL surveys among cancer patients. Response shift is where a person's perception of their illness and its treatment changes over time as an adaptive response to living with a chronic or life threatening illness, such as cancer, and its consequences. People living with such an illness amend their internal values and personal construction of what constitutes a satisfactory quality of life to take account of their changed and changing circumstances (Sprangers & Schwartz, 1999). As a
result, it is not uncommon to find that QOL measurements in people affected by cancer do not differ from scores within the normal population, despite the presence of disease or treatment related symptoms that could be considered disruptive to everyday activities.

Apart from the methodological limitations of retrospective cross-sectional surveys, this review also highlighted weaknesses such as reliance on small samples, lack of control groups and heterogeneity of samples in terms of primary diagnosis, stage of disease and type of treatment(s). In longitudinal studies, methodological weakness resulted from attrition in participant response rates over time and failure to analyse the characteristics of non-responders (Vistad, Fossa & Dahl, 2006).

While this was a comprehensive review of QOL studies in women treated for cervical cancer, a number of studies pertinent to this thesis were excluded as a result of Vistad, Fossa & Dahl’s (2006) strict inclusion criteria. Studies where the sample comprised women treated for endometrial cancer, where the research instruments may not have used patient self-report, or where multiple dimensions of quality of life were not included, such as a limited focus on vaginal toxicity, were all excluded from their review. Furthermore, studies which adopted a qualitative research methodology and those which focused on the sexual well-being of partners of women treated for gynaecological cancer were also omitted. The remainder of this section is devoted to those studies which add to our understanding of the sexual consequences of cervical and endometrial cancer and its treatment but which did not appear in Vistad et al’s (2006) critical review.

Pieterse et al (2006) conducted a questionnaire survey of 94 women treated for cervical cancer with radical hysterectomy and lymphadenectomy, comparing women who had surgery alone with those who received adjuvant radiotherapy (38% of sample) and with 224 age-matched controls. Women completed a 14-item self-report questionnaire pre-treatment and at three, 12 and 24 months post-treatment. The questionnaire included nine items (recent sexual activity level, sexual interest, vaginal lubrication associated with arousal, vaginal dryness, vaginal stenosis or shortening, dyspareunia, reduced labial / thigh sensation, anorgasmia associated with coitus, sexual dissatisfaction) related to sexual (dys)function.

A finding of note was that there appeared to be a lower level of recent sexual activity, low sexual interest and higher prevalence of dyspareunia among patients prior to commencing treatment when compared to age-matched controls. This suggests that the
symptoms of cervical cancer, knowledge of a cancer diagnosis and the prospect of treatment may all have an impact on female sexuality even before treatment begins. At three months post-treatment the authors found that women who had received adjuvant radiotherapy were less sexually active than women treated by surgery alone. However, Pieterse et al. (2006) found no difference in other sexual aspects at 24 months post-treatment. These findings also suggest that the autonomic nerve damage caused by surgery plays a crucial role in the aetiology of bladder, bowel and sexual dysfunction after radical hysterectomy and lymphadenectomy, hence the move towards using nerve sparing techniques in the surgical management of these women (Pieterse et al, 2006).

One of the few prospective longitudinal studies to explore the sexual consequences of gynaecological cancer treatment was that of Kylstra et al (1999). This study recruited 42 women with early stage (FIGO stage I and II) cervical and 10 women with early endometrial cancer treated by surgery alone or combined with radiotherapy (n = 13) and compared them with 103 healthy women controls. Women's sexual functioning was assessed immediately pre-treatment and at six and 12 months post-treatment using a multi-dimensional questionnaire: Questionnaire for Screening Sexual Dysfunctions - Short Form (QSD-SF). This questionnaire included items assessing frequency of sexual contact, (dis-) satisfaction with sexual life and the evolution of sexual response changes during the women's rehabilitation period affecting sexual desire, arousal, orgasm and resolution. The study is marred by a small heterogeneous sample and it was not possible to identify specific trends in the results according to treatment modality or diagnostic group. However, overall results indicated no significant difference between women treated for cancer and the healthy control group in relation to the frequency of sexual contact or level of sexual satisfaction across time. At 12 months post-treatment there were vaginal lubrication problems encountered by women who had received radiotherapy compared to their pre-treatment sexual health and to healthy controls. These authors do, however, express caution in the interpretation of these results, suggesting response shift as an important explanatory factor in women's tendency to moderate the importance of their sexual well-being within the context of a life-threatening illness (Sprangers & Schwartz, 1999). One aspect of the findings that contrasts with the British studies reviewed was that 67% of this Dutch sample of women had discussed the sexual consequences of their treatment by six months post-completion. Seventy-nine per cent of women were satisfied with the information obtained and their medical specialist was cited by 92% of women as the main source of information (Kylstra et al. 1999).
Another feature of the research studies exploring female sexual difficulties associated with a diagnosis of cancer is the extent to which emphasis is placed on an individual's functional ability to engage in sexual expression as opposed to viewing sexual expression as embracing psychological and relational elements so central to a woman's sexual well-being. One of the few researchers to consistently place emphasis on the influence of women's personal sexual construct on sexual expression is Barbara Andersen, a psychologist based in the United States. Andersen et al (1997) developed a theoretical model that could be used to predict women most likely to develop post-treatment sexual difficulties and thus warrant specific assessment and clinical intervention. Sexual self-schema represents a dynamic and multifaceted set of views held by the woman about herself, specifically as they relate to her sexual identity or sexual self construct. Andersen et al. (1997, p.221) describe sexual self-schema as:

"...a cognitive view about sexual aspects of oneself; it is derived from past experience, it is manifest in current experience, and it guides the processing of domain-relevant social information. When well articulated, it functions not only as a quick referent of one's sexual history but also as a point of origin for information-j judgements, decisions, inferences, predictions, and behaviours – about the current and future sexual self. In addition to regulating intrapersonal processes, sexual schema also appears to mediate interpersonal processes, the most obvious being sexuality within relationships."

The concept of sexual self-schema has been operationalised for research purposes to consist of a 24-item trait adjective measure representing three dimensions of: loving – romantic, direct-open, and embarrassment-conservatism. In their retrospective survey of 61 women with a variety of gynaecological cancer diagnoses (including 25 women with cervical and 25 endometrial cancer) and 74 healthy age-matched controls they found that 35% of women with cancer and 20% of the control group were not sexually active (engaging in sexual intercourse once per month over two specific six month periods prior to study commencement), with lack of a partner being cited as the most common reason. Prior to treatment there was no difference between the groups in frequency of sexual intercourse or the women’s global rating of their sexual lives. At a mean of 18 months after treatment completion, women with cancer who were sexually active at baseline reported less frequent coital and non-coital sexual expression (p<0.05, p<0.01) compared to healthy controls. More specifically they reported lower levels of sexual desire (p<0.001), lower sexual excitement (p<0.0001) and overall lower sexual responsiveness (p<0.001). Multiple regression analyses explored the relationship between pre-diagnosis sexual
functioning, extent of disease / treatment, current menopausal symptoms, sexual self-schema and current levels of reported sexual morbidity. The findings suggested that women with a negative sexual self-schema reported lower desire, excitement, disrupted orgasmic response and overall lower levels of sexual responsiveness than women with a positive self-schema. Sexual self-schema as an individual variable accounted for 28% of the variance observed in women's current level of sexual responsiveness (Andersen et al. 1997) with the other variables (prior levels of sexual activity, extent of cancer treatment and menopausal symptoms) accounting collectively for an additional six per cent of the variance observed.

This study suggests that sexual self-schema accounted for a significant proportion (28%) of predicted current sexual responsiveness in women, while in predictions of their sexual behaviour, pre-treatment levels of sexual activity, extent of disease / treatment and menopausal symptoms accounted for 42% of the variance, with sexual self-schema adding a further six per cent. These results highlight an important and often neglected issue in the oncology literature which is that heterosexual women's sexual behaviour, particularly frequency of sexual intercourse, is more likely to be dictated by the male partner's preferences. In contrast, the domain of female sexuality which is governed principally by the woman is her sexual responsiveness as manifest through individual patterns of desire, arousal and orgasm. These aspects of female sexuality are thus more closely associated with her internalised sexual self-schema or construct. These results suggest that an assessment model incorporating relevant medical, relational and psychological factors is needed to adequately predict which women are most likely to experience sexual difficulties associated with their cancer experience.

While this review of the biomedical literature has focused predominantly on critical appraisal of more recently published studies (2007-1994) it is appropriate to include two comprehensive literature reviews of older literature in order to present an historical perspective of research on female sexuality within the oncology literature. The first review of interest is that of Andersen & Van Der Does (1994) who explored the international literature in this topic from 1955-1994. While the methodology and specific parameters of the review were not stated, one of their more interesting findings was that there did not appear to be any obvious international differences in the type or degree of sexual morbidity reported by these studies. They noted a single study from Africa which reported a significantly higher level of post-radiotherapy sexual inactivity (75% of women) compared
to the 20-30% of women reported in studies from other regions of the world. This Nigerian study also found that 27% of women experienced divorce or separation after completion of cancer treatment, a relationship outcome that may have specific cultural explanations.

In reviewing radiotherapy and combined modality management studies Andersen & Van Der Does (1994) found that 40% of women reported a reduced frequency of sexual activity and disruption to one or more phases of the sexual response cycle (desire, arousal or orgasm) were experienced by 40-50%, with dyspareunia affecting between 25-35% of women. Overall trends from this literature review revealed a number of factors that appear to moderate psychosexual outcomes for women. As one might expect the more radical and extensive the treatment required to control the disease, the greater likelihood of psychological and psychosexual morbidity as a rehabilitation issue. Older women tended to be less distressed than younger women by altered sexual function. Women's overall QOL and adjustment post-treatment was considered good, albeit that sexual disruption of varying duration and severity was predicted to affect the majority of women. Whether sexual difficulties became an enduring and distressing problem for women and couples was probably related to the woman's psychological well-being overall and more specifically her sexual self-esteem and self-concept (Andersen & Van Der Does, 1994).

In critiquing the methodological limitations of studies Andersen and Van Der Does (1994) suggest that the rigour of more recent research has evolved from small descriptive studies and case reports to a greater number of prospective longitudinal studies more capable of producing valid and reliable data on which to base the subsequent development and testing of clinical interventions in a number of countries. While I may agree with this appraisal from a narrow biomedical or functionalist perspective, few of even the most recent studies incorporate an adequate appraisal of psychological and relational aspects of sexuality and sexual expression. This incomplete picture of the nature of female sexual difficulties associated with pelvic radiotherapy, together with our inability to regularly and effectively provide sexual health assessment or information in clinical practice suggests the development of rehabilitative intervention research may be premature if we cannot adequately influence current oncology practice given the existing evidence base.

Weijmar Schultz et al. (1992) reviewed literature from 1950-1991, analysing 44 post-treatment and 17 pre-post treatment studies. Their review covered a similar publication time period to that of Andersen and Van Der Does (1994) and so specific study findings will not be discussed here. An interesting aspect of this review was a critical appraisal of
future research directions that ought to be pursued by oncologists in order to reach an improved understanding of the sexual consequences of cancer treatment for women. They suggested the development of more precise pathophysiological measures of, for example, atrophic and stenotic changes in the vagina to be combined with psycho-physiological assessment in order to fully appreciate the relationship between treatment related physical morbidity, aetiology of specific organic sexual dysfunction and the woman's psychological and sexual responses to these changes.

The specific contribution of psychological (and here I would include relational or interpersonal perspectives) research in this field would assist the development and testing of clinical assessment methods that could be used to screen women to identify those most at risk of developing post-treatment sexual difficulties. Such assessment strategies could also identify those women and couples where there are pre-morbid sexual and relationship issues that indicate pre-treatment supportive care or referral may be warranted. As with Andersen and Van Der Does (1994) these authors lament the lack of intervention studies, particularly those that develop and test couple interventions.

Twelve years after this review we have a number of pharmacological interventions that have been tested in large randomised controlled trials, together with nationally approved clinical guidelines for the management of erectile dysfunction (ED), including ED caused by pelvic surgery (for prostate, bladder or rectal cancer), radiation or hormone therapy for cancer. However, simplistic pharmacological interventions for female sexual difficulties have proven elusive thus far (Tiefer, 2006) and funding for psychological interventions is notoriously difficult to secure.

Qualitative studies of treatment-induced sexual difficulties such as that by Juraskova et al. (2003) were not included in Vistad, Fossa and Dahl's (2006) critical review. This phenomenological study conducted in-depth interviews with 20 women (stage I and II cervical or endometrial cancer) and two male partners up to two years post-treatment. Interestingly, women without a current partner were excluded from this study, suggesting a somewhat narrow relational conceptualisation of female sexuality and sexual expression even in studies within an interpretive paradigm.

Analysis of interview transcripts used a grounded theory approach and the key themes emergent from this qualitative analysis broadly concurred with the results obtained from larger quantitative studies in the published literature. Juraskova et al. (2003) found that women who had received radiotherapy alone (particularly combined external beam and brachytherapy) or in combination with surgery (n = 11) were more likely to experience
negative changes in their sexual function and satisfaction post-treatment. Only 50% of these women resumed sexual activity post-treatment, noting reduced vaginal lubrication, dyspareunia and awareness of vaginal shortening (40%) as contributing to some of their sexual difficulties. As in the biomedical literature reviewed sexual activity was not specifically defined for this study but implied to be heterosexual vaginal intercourse. The main emergent themes were:

- Perceptions of femininity and reproductive organs
- Attitudes regarding initial re-commencement of sexual activity
- Perceptions of sexuality and intimacy issues from the patient’s perspective
- Women’s perspectives on partner’s coping with the changes in sexual functioning
- Impact of treatment procedures and residual long-term side effects
- Mediating effects of coping style on patient’s perceptions of treatment and its side-effects
- Ongoing psychological support
- Dilators and other aids

These authors noted that altered femininity was an important aspect of sexual recovery post-treatment, with pre-menopausal women most likely to grieve for the loss of their reproductive capacity, regardless of whether or not they had completed their family. Many of the women were fearful of resumption of sexual intercourse and found it difficult to discuss this openly with partners, preferring to deny their own wishes in order to satisfy the perceived sexual needs of their partner. While most women felt their partners shared this fear, some interpreted sexual abstinence as disinterest or rejection of them as women. Where women experienced their relationship to be supportive and accommodating they found this affirming and “healing” for their sexual recovery. Women tended to equate satisfactory sexual expression with the presence of intimacy as experienced through sensuality, disclosure and reassurance in their relationship as opposed to coital aspects, a dimension more commonly associated with male partner’s satisfaction with sexual expression (Juraskova et al. 2003).

Women felt better able to cope with side effects of treatment when they understood the aetiology of such effects and felt prepared for their development. Some women found that doctors over-estimated their knowledge of the anatomical and physiological changes
brought about by their cancer therapy and were angry and resentful when experiencing unforeseen effects that could serve to undermine their sense of mastery or control. Even when physical recovery was complete these women expressed a need for ongoing support where someone would acknowledge their progress and offer reassurance. Perhaps the resolution or reduction of physical symptoms associated with disease and treatment led to a shift in focus or priorities whereby women then wanted to devote more time to address the emotional and psychosexual elements of their illness experience (Juraskova et al. 2003). This finding has implications for the optimal timing of information provision and support with regards to sexual adjustment post-treatment.

Butler et al. (1998) also conducted a qualitative study of 17 women treated for cervical or endometrial cancer two to 18 months previously. Consistent with the other qualitative studies reviewed, this paper adopted a broader definition of sexuality as a concept with sexual function as only one dimension of how women viewed themselves as sexual beings. The importance of relationships with their medical team, family and friends was central to how women negotiated meeting their sexual information and support needs. Women interpreted the absence of sexual health discussions with medical and nursing staff as implying that their sexuality was not a medical concern given their doctor’s priorities in treating cancer. Women experienced a loss of both sexual and gender identity associated with their cancer treatment and resulting changes in body image and fertility. Using a vaginal dilator was perceived as difficult by this sample of women and its use inconsistent. The nurses in this study rarely discussed sexual functioning with women, teaching dilator use as a predominantly procedural or technical intervention. Overall Butler et al. (1998) cautioned against care systems and professionals viewing women with altered sexuality emanating from cancer treatment as inherently “dysfunctional”. The adoption of such a view could be seen to denote a value judgement that serves to reduce the likelihood they will seek assistance with sexual health difficulties from health professionals.

Another qualitative study which relied predominantly on semi-structured interview data to explore the sexual adaptation of 19 women following surgery and radiotherapy for endometrial cancer was a mixed method study by Lamb & Sheldon (1994). Data from body image, self-esteem and sexual functioning visual analogue scales and self-concept scores were analysed in relation to patient’s demographic and medical history. In contrast to the younger age group of women affected by cervical cancer, 42% of this study sample included women aged 60-65 years. Themes emergent from a content analysis of the
interview transcripts included: the intimate relationship before cancer, effects of symptoms and diagnosis of cancer on self-concept and sexual adaptation, ramifications of treatment, the influence of women’s partners on sexual adaptation and factors enhancing sexual adaptation. Lamb and Sheldon (1994, p.109) found that women attributed a negative meaning to their experience of vaginal bleeding, placing emphasis on the “lack of control” and not feeling clean as a consequence. The uncertainty of this distressing symptom appeared to be the most common deterrent to maintenance of intimate relations with their partner:

“...Before the operation, I think our sex life took a kind of nose dive, only because everything was so unpredictable. We never knew when I might start bleeding again. It was hard enough to keep the bed clean. I think we both felt sex would just make things worse.” (Lamb & Sheldon, 1994, p.109)

The majority of women in the study (n = 13, 68%) had been married for over 20 years and talked of their relationships as a close intimate bond and key source of support. What was interesting was that these couple’s communication patterns appeared to be unchanged by the illness experience, remaining open and supportive.

At diagnosis women’s priorities were issues of life and death, with body image and sexuality relegated to lesser importance. After treatment, sexual adaptation seemed to be closely influenced by changes in self-esteem and body image associated with surgery and radiotherapy. Women noted that sexual adaptation was largely dictated by partner support and by their own long-term reactions to their illness and its treatment. This adaptation was enhanced by fighting spirit and optimism, together with sources of external support such as partners, family, friends, cancer support and religious groups (Lamb & Sheldon, 1994). This study contrasts with those adopting quantitative research approaches in focusing less on sexual function and dysfunction and offering more detailed insights in relation to the emotional responses and meanings women attributed to their illness experience and its impact on their sexual identities and relationships.

2.5.1 Studies of couples affected by cervical or endometrial cancer and its treatment

The majority of biomedical studies exploring the sexual consequences of cervical cancer treatment focused on QOL and sexual issues in women alone, failing to take account of the central role played by the women’s intimate / sexual partner as a context for both psychosocial and psychosexual support and adjustment. A recent survey by DeGroot et al.
(2005) explored the range and intensity of psychosocial concerns in 26 couples where the woman had been treated for cervical cancer (stage I-IV) up to 24 months previously. The results indicated that women experienced greater intrusion by their illness than their male partners, noting particularly the effects this had on their relationships (p<0.05) and on intimacy (p<0.05). For the purpose of this study intimacy was defined as incorporating both the partner relationship and sexual expression.

As might be expected, current concerns were greater in couples where treatment completion was in the last 12 months (p<0.049), compared to those over 12 months post-treatment. Shorter term concerns included communication with the treatment team, relationship with partner and relationship with others. Persistent illness related concerns experienced by both women and their partners were highest in relation to prognosis, sexuality and ongoing communication with the treatment team.

Overall there was a high degree of agreement between women and their partners regarding the psychosocial impact of cervical cancer and its treatment. However, where divergence did occur was in the degree of concern expressed over time post-treatment. Men whose partners were over 12 months post-treatment expressed lower concern across all domains with the exception of prognosis and treatment issues. By comparison, women with cervical cancer maintained a high level of concern across four domains, namely cause of cancer, treatment issues, prognosis and sexuality. These findings are consistent with other studies in women with cervical cancer, indicating the enduring nature of concerns about sexuality and prognosis up to five years post-treatment (Bergmark et al. 1999; Cull et al. 1993). What DeGroot et al.’s (2005) study did highlight was the positive association between higher relationship discord and greater divergence in the intensity of concerns expressed by women and their partners. This finding suggests it may be important to explore and address the concerns of both women and their partners in the provision of information and support. Male partners expressed a strong wish to be involved and kept informed about their partner's illness, suggesting that excluding partners from such discussions could constitute an important supportive care omission (DeGroot et al. 2005).

In 1990 Van De Wiel et al conducted a pilot study of 16 male partners of women treated for gynaecological cancer 12 months previously. Semi-structured interviews were conducted by a male psychologist and the transcripts 'scored' using quantitative content analysis. The findings indicated that half of the men (n = 8) did not feel well-informed about their wife's illness and treatment and 12 of the 16 men experienced stress in trying to
provide support to their partner. While nine of the men felt they had a good quality of sexual relationship pre-treatment, this dropped to only four men 12 months after their partner’s treatment completed. The men commented that they found sex less satisfying when they could see their wife did not enjoy sex or achieve orgasm and this led to them experiencing feelings of incompetence and guilt. The researchers noted that men tended to adopt somewhat stereotypical masculine coping strategies during this stressful time, preferring to try to problem solve alone and not seek help for problems encountered. Furthermore they seldom reported trying any adaptive non-coital sexual strategies while intercourse was difficult, preferring simply to wait until their partner was willing to be sexual again. Nor did the men appear to discuss these sexual difficulties with their partner, making satisfactory resolution of problems less likely (Van De Wiel, 1990). Regression to rigid coping styles during periods of mutual stress associated with serious illness may indicate a need for health professionals to give greater attention to partner needs and couple communication patterns if sexual and relationship problems are to be reduced in the longer term.

Another small study (11 couples where the woman had been treated for cervical cancer) by the same principal author explored sexual satisfaction, physical expression and sexual self-esteem at six months post-treatment compared to 250 healthy controls using a validated 22 item self-report Dutch questionnaire (Van De Wiel et al. 1988). While this study purported to focus on couples affected by cervical cancer, the paper lacks details of specific partner data, although it did offer some interesting insights regarding women’s emotional motivation to engage in sexual intercourse. The authors suggested that women recently completed treatment may adapt to the sexual expectations of their partners as a consequence of lowered sexual self-esteem and an increased dependency on their intimate partner for support at a time of significant stress. Van De Wiel et al. (1988) suggested that some women may engage in sexual intercourse in order to maintain harmony and reduce the possibility of losing their relationship despite having little or no interest in engaging in sexual intercourse for themselves. As mentioned by DeGroot et al. (2005) these complex relationship factors suggest that it is important to address the needs of the woman, her partner and the couple in considering post-treatment sexual adjustment and support.
2.5.2 The Assessment of Vaginal Toxicity following Pelvic Radiotherapy Treatment in research and clinical practice

In addition to the studies exploring overall QOL or more specifically exploring the sexual well-being of women after pelvic radiotherapy for cervical or endometrial cancer a number of studies have chosen to specifically explore the prevalence and severity of vaginal toxicity. The development of vaginal stenosis or shortening as a late treatment effect is often considered the dominant mechanism for sexual difficulties among women receiving pelvic radiotherapy (Decruze *et al.* 1999) However, inadequate study of the range of sexual difficulties experienced (for example changes in levels of sexual desire / interest and reduced orgasmic response), the woman's psychological responses and relationship dynamics seriously undermines this assumed link.

Vaginal changes are inconsistently evaluated and reported within both clinical practice and research. In a recent audit of the prevalence of late severe side effects associated with radical radiotherapy for carcinoma of the cervix, no specific mention of vaginal toxicity was made while both urological and bowel toxicities were documented in detail (Denton *et al.* 2000). When vaginal toxicity is recorded, the prevalence of *stenosis* varies considerably, ranging from 1.6 - 88% (Nori *et al.* 1994; Noyes *et al.* 1995; Nunns *et al.* 2000; Lancaster 2004; Saibishkumar *et al.* 2006; Brand *et al.* 2006). The prevalence of stenosis tends to be reported as higher (24-88%) when it is being specifically evaluated within studies (Brand *et al.* 2006) as opposed to being noted as part of overall pelvic radiotherapy toxicity or QOL assessment. Variation in reporting may also be explained by differences in definition, the absence of a standardised approach for the measurement or grading of vaginal toxicity, the impact of co-variables related to treatment technique or combined modalities, disease and patient characteristics and a lack of adequate follow up to detect development of late treatment effects (Noyes *et al.* 1995; Weiss *et al.* 1999; Denton *et al.* 2000; Bruner *et al.* 2006). Hence the prevalence and severity of stenosis among women treated with pelvic radiotherapy, together with a satisfactory evidence base for appropriate intervention, remain elusive (Denton & Maher 2003; Bruner *et al.* 2006).

Exploration of the precise relationship between demonstrable vaginal toxicity and the nature and severity of sexual disruption was rarely explicitly discussed in the studies of vaginal toxicity reviewed. In a study of women following combined modality treatment for endometrial cancer (Nunns *et al.* 2000) the prevalence of vaginal stenosis was found to be as high as 54.7%. The sample comprised 75 women from a total of 252 who had received radiotherapy and where details of vaginal anatomy and sexual function had been recorded.
prospectively in medical records. The researchers used a standardised questionnaire to collect a brief sexual history after radiotherapy had been completed. This questionnaire contained items such as pre-treatment sexual activity, effects of radiotherapy on sexual function, dyspareunia, sexual desire and sexual frequency. Analysis compared findings from the questionnaire with those from digital vaginal examination by two experienced clinicians. Vaginal stenosis was defined in this study as the inability to pass two fingers into the vagina with ease.

Nunns et al. (2000) found that only 20 / 75 (26.7%) of the women were sexually active prior to treatment. Of this sub-group, 13 reported a reduction in frequency of sexual activity and reduced sexual interest post-radiotherapy and 12 women complained of dyspareunia, with evidence of objective stenosis recorded in seven women. Among the sexually active women, however, there were a number of other vaginal symptoms noted, namely vaginal vault scarring in 15, mucosal atrophy in 13 and telangectasia in 11 women. This may suggest that while the prevalence of vaginal stenosis may not correlate directly with sexual difficulties, the presence of other types of mucosal damage and reduced vaginal lubrication remain important contributory factors. This study also demonstrated that, depending on one's definition of what constitutes sexual activity, there may be a baseline low level of sexual activity among women with endometrial cancer (55 / 75, 66.7% women were not sexually active). This finding reinforces the importance of assessing what constitutes an individual woman and couple's frequency and nature of sexual expression as a baseline to use as comparison for evaluation of post-treatment sexual goals and adjustment.

Most studies explore the prevalence and nature of sexual difficulties experienced by women between six and 24 months after treatment completion. However, a small study (n = 16 women) by Flay and Matthews (1995) evaluated short term vaginal changes and altered sexual expression immediately before and after treatment and again at six and 14 weeks following pelvic radiotherapy. They used a non-validated questionnaire incorporating 5-point analogue scales to assess sexual interest, sexual satisfaction, relationship satisfaction, intercourse frequency and frequency of orgasm. As one might expect, overall sexual activity level was at its lowest at treatment completion. The most common reason cited by women for their altered sexual function was a feeling of vaginal shortening (64% at 14-week assessment). Analysis revealed that dyspareunia, vaginal bleeding, fear of bleeding and fear of recurrent disease were all contributory factors in the early weeks after diagnosis and treatment. Only sexual interest failed to return to pre-
treatment levels at the 14 week assessment. It is worthy of note that even though the women's frequency of intercourse at 14 weeks had returned to pre-treatment levels, 33% of women still reported extreme sexual dissatisfaction. This finding illustrates why frequency of intercourse alone is a poor measure of women's sexual enjoyment or satisfaction. Flay and Matthew's (1995) study was also one of the few to elicit from women the significance they ascribe to vaginal bleeding as a symptom and reminder of their illness. Fifty-six per cent of women before treatment reported bleeding or fear of causing bleeding as a reason for reduced sexual activity and 43% remained concerned at 14 wks post-RT. A number of vaginal symptoms were present at 14 weeks post-RT including vaginal narrowing (43%), vaginal dryness (43%) and vaginal bleeding (36%). Vaginal examination at this time revealed epithelial atrophy and telangiectasia in the upper vagina among the majority of women and vaginal stenosis had developed in two of the sample despite the short time post-treatment completion. While the sample size of this study is too small to generalise these findings it is also interesting to note that three out of 16 women reported major relationship difficulties related to their illness and treatment at 14 wks follow-up. Flay and Matthews (1995) recommend that a more proactive provision of counselling and practical advice regarding how to minimise sexual morbidity associated with treatment should be provided for women and their partners in recognition of the stress placed on intimate relationships.

More recent studies have attempted to explore vaginal toxicity in this patient group using measurement techniques and research designs that are methodologically more rigorous (Brand et al. 2006; Bruner et al. 2006). Bruner et al. (2006) reported on the reliability of using a vaginal sound (a modified plastic vaginal dilator 15cm length x 2.85cm diameter calibrated in cms) to measure changes in vaginal length following pelvic radiation. They tested the measurement of vaginal length in normal volunteers (two post-menopausal and five pre-menopausal women) using a total of 88 nurses and physicians to test the inter- and intra-rater reliability of this research instrument. Results indicated good reliability (using intra-class correlation coefficient) with 85% (75/88) of the measurement disagreements accounting for less than 1cm difference. This study also took account of the fact that the vagina is an elastic organ with the capacity to expand in relation to the number of insertions experienced by each volunteer. These authors referred to seminal sexology research by Masters and Johnson (1966) to estimate the length of the vagina at rest (measured from the posterior fourchette to the apex) at 7-9 cm, with a trans-cervical
width of 2cm. Previous research by Bruner et al. (1993) used a prototype of the vaginal sound and estimated women's vaginal length post-pelvic radiotherapy for cervical cancer to range from 7.75cm at 6-<12 months to 6.2 cm at >24 months.

As mentioned previously, emphasis within research and practice intervention appears to assume a direct relationship between severity of physical morbidity, such as vaginal stenosis and shortening, and the prevalence of sexual difficulties (Decruze et al. 1999; Bergmark et al. 1999; Denton & Maher 2003). However, as Bruner et al. (2006) comment, it is important to be able to formally evaluate the assumed relationship between altered vaginal length / calibre and sexual function in women who have received combined treatment modalities for both cervical and endometrial cancer. Women treated with pelvic radiotherapy for bladder, rectal and anal cancers should also be evaluated as vaginal toxicity and associated sexual difficulties have been a particularly neglected aspect of post-treatment toxicity assessment in this patient population as discussed in section 2.6 of this review. The ability to reliably measure changes in vaginal length and calibre post-treatment is one important pre-requisite for testing the development and efficacy of interventions designed to ameliorate vaginal late effects (Bruner et al. 2006). The lack of a reliable measurement instrument may be one of the reasons that the efficacy of vaginal dilation as a prophylactic intervention in the maintenance of vaginal health has not been rigorously studied to date.

One of the few prospective studies exploring the aetiology of vaginal stenosis post-radiotherapy for cervical cancer is that of Brand et al (2006). This Australian study reviewed the medical records of 179 women (mean age 58.6 yrs) where data regarding the incidence, timing and severity of vaginal stenosis had been systematically graded and recorded. Demographic data had been recorded to determine whether or not there were any predisposing patient or treatment factors for the development of stenosis. All of these women received radiotherapy as a primary treatment (7% also had a hysterectomy) and 30 women (16%) had received concurrent chemo-radiation. The only factor that appeared to predispose women to develop vaginal stenosis post-treatment was if they were aged greater than 50 yrs (p = 0.02). The authors speculated that this was probably a result of the combined impact of reduced vaginal oestrogen and / or a lack of sexual activity in older women. This latter assumption is intriguing given they had not recorded levels of sexual activity as part of the demographic data for their study.

Grade I vaginal toxicity (partial stenosis or shortening but not complete occlusion) was noted in 27% (n = 48) of their sample, with a further 11% (n = 19) found to have grade
II (complete vaginal occlusion), 1.7% (n = 3) had grade III (radio necrotic ulcer formation) and 2.3% (n = 4) grade IV toxicity (fistula formation to bowel, bladder or peritoneum). A total of 102 women (58%) had no vaginal stenosis, with only flimsy vaginal adhesions that could be easily broken down on vaginal examination. Vaginal toxicity appeared to develop independently of the presence or severity of either bladder or bowel toxicity.

The results of this study also provided information that could be used as a clinical indicator of the optimal time for promotion of vaginal dilation post-radiotherapy as a prophylactic intervention for women routinely advocated across the UK. The mean time to development of any degree of stenotic changes was 9.6 months, with a median of 7.5 months from completion of pelvic radiotherapy (Brand et al. 2006). These findings contrast with an earlier study (Katz et al, 2001) where vaginal shortening was detected on radiotherapy planning films during combined external beam and brachytherapy treatments, although the sample was too small (n=41) to draw any firm conclusions.

It was interesting to note that at the time of Brand et al’s (2006) study the routine use of vaginal dilators post-treatment as an intervention to reduce the likelihood of developing vaginal stenosis or shortening was not advocated in Australia. White and Faithfull (2006) recently conducted the first UK survey of current practice in vaginal dilation associated with pelvic radiotherapy. Findings highlighted areas of consensus and divergence in relation to the target group for this intervention, patient education content, sexual health assessment and evaluation of compliance with vaginal dilation. Clinical nurse specialists were revealed as the key professionals engaged in any sexual health assessment, although the precise scope and depth of assessment varied considerably. The content of discussions could include enquiry about the impact of treatment on sexual health, baseline frequency of sexual contact, the woman’s pre-treatment menopausal status and whether or not she was receiving hormone replacement therapy (HRT), consideration of treatment impact upon the woman’s partner, elicitation of pre-existing sexual difficulties and sources of sexual counselling and support. Of some concern was that 32% of respondents said they were not aware of anyone in particular taking responsibility for the evaluation of compliance with vaginal dilation. Only 19% of respondents combined this element of practice with an overall evaluation of radiotherapy toxicity and only 11% considered placing the provision of vaginal dilators within a wider context of post treatment sexual readjustment.

The apparent lack of professional interest in evaluation of compliance with and efficacy of vaginal dilation as a prophylactic intervention is highlighted by studies such as
that of Juraskova et al. (2003). In their qualitative study 11 women had received radiotherapy, yet only seven had been given a set of vaginal dilators to use to prevent the development of vaginal stenosis and shortening. Of those seven women, three had tried to use them but failed due to discomfort and / or embarrassment and the remaining four had not even attempted their use.

2.6 The Sexual Consequences of Pelvic Radiotherapy in Combined Modality Treatment for Non-Gynaecological (Bladder, Anal and Rectal) Cancers

Evolving treatments in bladder cancer have attempted to reduce the morbidity of radical surgery in favour of organ conserving techniques while ensuring equivalence of disease control (both in terms of local recurrence and development of metastases). Radical treatment of bladder cancer can result in cure rates of 60%, but not without substantial impact on quality of life (QOL). There are few longitudinal prospective studies of the late effects of radiotherapy (RT) in bladder cancer, the majority are either case control or cross-sectional studies, retrospective, have small samples and tend not to include many women as this is a disease that mainly affects men. Hence, little is known about the sexual difficulties associated with the treatment of bladder cancer in women after radical pelvic radiotherapy (Fokdal et al. 2004).

The impact of treatment on QOL in people with bladder cancer can be attributed to the extent of pelvic surgery (radical cystectomy and urinary diversion), irradiation of pelvic structures and from the combined impact of urological, bowel and sexual dysfunction associated with both modalities (Zietman & Skinner, 2005).

Out of total study sample of 48, 12 women (25%) participated in a longitudinal study (median follow up 6.3 years) of QOL following transurethral resection of bladder tumour in conjunction with chemo-radiation (Zeitman et al. 2003). While the majority of men answered questions in relation to sexual function the authors reported that:

"In the assessment of sexual function, most women in the [hospital name] study preferred not to answer the questions and no data were therefore available for them." (Zietman & Skinner, 2005 p.58).

No further explanation of the women's apparent reticence was offered nor was there any attempt to seek explanation from the women as to why they felt unable to complete these items.
Fokdal et al’s (2004) telephone survey of bladder, bowel and sexual function following radical RT for bladder cancer recruited seven (13% of total patient sample) female patients and nine women to their control group. Of the seven women with bladder cancer who participated only two were currently sexually active. Five of the women reported lack of sexual desire, four experienced lack of sexual satisfaction and two reported that the RT had had a moderate impact on their current sexual life. A combination of small sample size and the fact that the control group women had a lower mean age than female patients in the study (66 compared to 76 years of age) meant that no clear conclusions could be drawn from the scant data presented.

A study by Henningshon et al. (2002) also failed to recruit sufficient women to generate useful findings on female sexual difficulties following radical radiotherapy for bladder cancer. Of a total patient sample of 48 who had received radiotherapy and met the study inclusion criteria, only 13 women (27%) were recruited, with a median age of 81 years. Of the 10 women who received radiotherapy, none were sexually active during the period of the study and all reported either no or low sexual interest. No further detail about the sexual concerns of these women was reported in this paper so we remain uncertain as to whether or not their loss of sexual interest pre-dated their diagnosis or treatment or arose as a consequence of their illness. We also have no indication as to whether or not this loss of sexual interest constituted a problem for these women, whether they had a current partner, and if so whether this constituted a difficulty for them as a couple.

Current management of rectal cancer also favours organ preservation wherever possible, frequently combining pre-operative chemo-radiation and total mesorectal excision (TME) with sphincter preservation to avoid permanent stoma formation. A recent Canadian study (Hendren et al. 2005) acknowledged the scant research evidence regarding female sexual difficulties after treatment of non-gynaecological cancers and specifically focused on their prevalence following surgery for rectal cancer. They found that of the 81 women who took part in their study, 47% reported experiencing a “sexual difficulty” prior to treatment, although analysis of the specific nature of these difficulties was not included in the research report. Of the 47 (61%) women who were sexually active pre-operatively, only 25 (31.7%) remained so following surgical treatment. In this study a total of 31 (38.3%) women received radiotherapy although no detail was given as to whether this was short or long-course radiotherapy, whether concurrent chemotherapy was administered, or whether the radiotherapy was delivered pre- or post-operatively. Of
the 31 women who had received adjuvant radiotherapy, only eight (32%) were currently sexually active while 23 (42.6%) were not.

Nineteen women agreed that surgery had made their sexual life worse than it was before treatment, 14 (73.7%) of whom had also received pelvic radiotherapy. Sixteen (94.1%) of these women reported specific sexual problems that developed following treatment including libido problems (72.7%), arousal problems (66.7%), lubrication problems (78.6%), orgasm problems (75%) and dyspareunia (100%). In addition, 13 of these 16 women reported that their vagina felt “smaller” or “tighter” after rectal surgery. A multivariate analysis revealed that pelvic radiotherapy was one of the factors more likely to be associated with the patient opinion that “surgery made their sexual life worse” while age and pre-existing sexual difficulties were not predictive of a poorer quality of post-treatment sexual life (Hendren et al. 2005).

This study attempted to improve the reliability and validity of its findings by using both gender and disease specific validated instruments (Female Sexual Function Index [FSFI] and EORTC QLQ-CR38 sexual function and sexual enjoyment domains) together with a locally developed questionnaire which incorporated important aspects such as body image, psychological and physical treatment effects to assess the multi-faceted nature of female sexual difficulties associated with multi-modal cancer therapy. Unfortunately, as the study assumed rectal surgery was the principle causative agent in both male and female sexual dysfunction, no detailed analysis or interpretation is offered regarding the potential compounding effects of adjuvant pelvic radiotherapy for these women. Using the FSFI, 39% of sexually active women and 62% of women in the study overall had abnormal scores, indicating clinically significant sexual dysfunction (despite the routine use of nerve-sparing surgery) when compared to that expected within a normal female population of comparable age.

A finding from Hendren et al.’s (2005) study that is particularly relevant to this thesis is the fact that only 9% of women compared to 39% of men recalled discussing the sexual impact of treatment preoperatively with their medical team. This may represent gendered assumptions about sexual expression whereby functionality is of greater importance to a man because of his active sexual role in both hetero and homo-sexual sexual expression as opposed to the need for receptivity in the female.

The issue of informed consent was specifically investigated in Chorost et al.’s (2000) research which used both medical record review and telephone interview (for the female patients only) to explore the pre-treatment discussion of treatment-related sexual
disruption including the prevalence of sexual difficulties following surgery with or without RT. Sixteen of the 52 study participants were women, only four of whom had received both surgery and radiotherapy. Documentation of pre-treatment discussion of the risk of postsurgical sexual difficulties was absent in 37/52 (71%) of the medical records reviewed. In the 16 records of female patients there was no documentation of any discussion of sexual dysfunction risk associated with treatment. As a result of this lack of detail in routine clinical documentation the researchers compiled a structured interview schedule to elicit female sexual difficulties via telephone interview. They used a female social worker to conduct all of the interviews in acknowledgement that women may be reluctant to discuss sexual concerns with a male practitioner. However, only one woman who had had an abdomino-perineal excision of the rectum (APR) alone reported experiencing vaginal dryness and reduced frequency of sexual intercourse. No other sexual difficulties were elicited from the remaining 15 women (Chorost et al. 2000). No details were given in the paper of the time elapsed post-treatment for any of the participant responses and the small sample size of both male and female patients may explain why the majority of their results failed to reach statistical significance.

The first large scale (n = 990) prospective randomised trial comparing sexual function at 24 months in women who had total mesorectal excision (TME) alone versus TME plus pre-operative short-course (25 Gy over five days) pelvic radiotherapy (RT) was conducted in the Netherlands (Marijnen et al. 2005). This study stratified its sample to analyse whether or not the type of rectal surgery performed (low anterior resection [LAR] versus abdomino-perineal excision of rectum [APR]) had a significant impact on the nature of bowel, urinary or sexual function post-treatment. One hundred and seventy-nine women received TME plus RT while 186 women had TME alone. Assessment of sexual function took place from three to 24 months post-treatment using the Rotterdam Symptom Checklist with added questions relating to sexual activity, sexual attractiveness, sexual interest, dyspareunia, vaginal dryness, sexual pleasure and sexual satisfaction.

As in Hendren et al.’s (2005) study, only 53% of women offered TME plus RT and 50% of those offered TME alone were sexually active prior to their cancer treatment. Pre-treatment assessment of sexual well-being is an important baseline for the subsequent identification and management of post-treatment sexual morbidity and yet in clinical practice this rarely happens, particularly among female patients. Marijnen et al.’s (2005) findings explored changes in sexual function solely among women who were sexually
active before treatment. As in most studies exploring sexual morbidity associated with cancer treatment, sexual activity is taken to mean women engaging in heterosexual intercourse. This is an assumed definition as none of the studies reviewed to date have defined precisely what they meant by the term “sexual activity”.

Among the female patients (n=186 TME alone versus 179 TME + RT) who took part in the study, post-treatment sexual function was worse for those women who had received pelvic radiotherapy (p<0.001) at all assessment time points compared to women who had received rectal surgery alone. Vaginal dryness and dyspareunia were increased for all women, with no statistically significant difference between those who had received radiotherapy and those having surgery alone. The type of surgery women received remains a contributory factor in determining sexual difficulties even at 24 months post-treatment completion. Women who had an abdomino-perineal excision of the rectum (APR) were more likely to experience dyspareunia than women who had a low anterior resection of the rectum (LAR) without stoma formation (p= 0.006).

External beam radiotherapy (RT) can cause damage to peripheral nerves, probably through its detrimental effect on the capillaries in the neurovascular bundles. RT can also cause deterioration in smooth muscle structure and function, with diffuse fibrosis and mucosal irritation which may explain the dyspareunia commonly encountered by women in these studies. These pathophysiological changes, induced by pelvic RT, compound the nerve damage (whether permanent or temporary) and vascular disruption caused by the various operative approaches adopted (Mannaerts et al. 2001). The clinical significance of these changes relates to the need to improve pre-treatment discussion of the combined impact of multi-modal treatment for rectal cancer regardless of whether the woman is being seen in a surgical, medical or clinical oncology context for her initial treatment discussions. Lead clinicians and specialist nurses must be able to demonstrate awareness of sexual sequelae arising from each modality used in the management of an individual woman’s illness as opposed to focusing solely on the sexual consequences associated with their discipline (surgery, clinical or medical oncology) of origin.

In reviewing the biomedical literature on the prevalence and nature of female sexual difficulties associated with multi-modal cancer therapy it is evident that the level of detail presented in the results is closely related to the research instruments used and thus the type and scope of questions and domains of sexual function assessed or omitted by the assessment methodology in question. In general, assessment of sexual difficulties is
less detailed when a limited number of global scores (sexual functioning, sexual enjoyment, sexual dysfunction of women) are used within broader QOL instruments such as the EORTC QLQ-C38. For example, the validity and reliability of findings from Allal et al.'s (2005) prospective longitudinal study were adversely affected by both the small sample size (n = 17 women / 53 participants) and the limited detail presented regarding the specific sexual difficulties experienced by women treated for rectal cancer. Sexual functioning and enjoyment scores recorded both pre and post-RT were presented as combined gender scores which masks gender specific norms and treatment related changes in this patient group. Neither of these measures revealed a statistically significant difference when comparing scores one week prior to commencement of pelvic radiotherapy with those obtained at 12 months post-treatment. Only sexual dysfunction, a global term that was not defined or divided into its component parts, was reported by separate gender with results demonstrating a statistically significant increase in sexual dysfunction in men (median pre-RT score = 17 and post-RT score 83, p = 0.0045) at one year post-RT while in women the change in median scores (median pre-RT score = 0 and post-RT score 33, p = 0.18) did not reach statistical significance. Another score thought to be closely related to sexual well-being that is worthy of mention was the deterioration in body image assessed at 12 months post-treatment: pre-RT median score 100 (range 11-100) and post-RT median score of 89 (range 11-100), p = 0.068.

Engel et al. (2003) also used the EORTC QLQ-C38 questionnaire in a prospective postal survey of QOL in patients treated for rectal cancer (with surgery and RT / adjuvant chemotherapy) spanning a period of four years post completion of treatment. As one might expect, rates of response reduced over time with only 48 respondents returning the questionnaires across all four annual assessment points. The authors noted that fewer women responded to the questions relating to sexual function, but no details were given of the precise number of responses received or of any attempt to explore the reasons for poor response to these items. Mean scores for combined genders were reported for both sexual functioning and sexual enjoyment, with separate male and female sex problem scores illustrating some gender difference in the results of this study. Male sexual problem mean scores were lower (maximum score of 100 indicates good function, 0 represents poor function) than female sexual problem scores across each of the four annual assessment points, indicating that men appeared to experience worse sexual function post-treatment. Female sexual problem mean scores were 64 at year 1, 61.1 at year 2, 60.2 at year 3 and 66.7 at year 4, compared to male mean scores of 43.3 at year1, 45.3 at
year 2, 39.0 at year 3 and 31.5 at year 4. The reduction in scores across the four year period may not only indicate age related changes in sexual function but also represent radiation induced late effects beginning to impact on function across time. As there was no sub-group analysis of patients who had received combined treatment (TME plus RT) compared to those who had surgery alone, the specific contribution of RT to changes in sexual function was impossible to determine. In addition, no normal age matched control group were used and so it is not possible to say that these changes in function were not at least in part representative of changes that may be seen in a normal population of older adults.

A recent study of patients treated by chemo-radiation for anal cancer (Jephcott et al. 2004) also used the EORTC QLQ-C38 site specific quality of life questionnaire to evaluate treatment impact on female sexual function at a median of 62 months post diagnosis, comparing patients (n = 37) with an age and gender matched control group of volunteers. There was no significant difference in the mean scores for body image and sexual functioning (p = 0.255 and 0.360 respectively) between patients and controls but the mean patient score for sexual enjoyment was only 46 (max. score = 100) compared to a mean score of 70 among the volunteers (p = 0.016).

When female sexual problems were compared again a statistically significant result was obtained with female patients reaching a mean score of 51 (max. score = 100) compared to matched volunteer mean scores of 21 (p = 0.016) where a higher score indicates increasing difficulty. As in many of the studies reviewed, treatment related changes in male sexual dysfunction reached a higher level of significance (p = <0.001) when compared to self-reported impact of female sexual difficulties. However, this should not be taken to mean that sexual function is less important to women of a similar age group; it may be that the QOL instruments in use lack the specificity or scope to detect the specific types of female sexual difficulties experienced by these women.

In a number of studies using the EORTC QLQ-C38 the presentation of combined gender mean scores made any detailed analysis of female sexual difficulties impossible. It is also likely that combined gender score means were skewed by the higher prevalence of sexual problems in a larger sample of men in the studies, together with lower female response rates for sexual items in the overall QOL questionnaire. As has been mentioned previously, this QOL instrument may lack the necessary detail to adequately capture the specific sexual difficulties experienced by women and as such fail to produce results that are valid and reliable. Results emanating from the EORTC QLQ-C38 may benefit from
supplementation with a more detailed questionnaire regarding specific female sexual difficulties to generate more clinically meaningful results. Where sexual items in an overall QOL instrument are answered less often by women than by men it may prove useful to enquire as to the reasons for such a gender disparity. Such gender differences in response rates could reflect design insensitivities in the instrument or a social reticence among women to offer details about their sexual lives.

Temple et al. (2003) reviewed earlier studies that had evaluated the impact of RT on functional outcomes (normally bowel, bladder and sexual functioning) in patients with rectal cancer, concluding that there were a number of methodological weaknesses that undermined confidence in the evidence base available at that time. The studies reviewed tended to have a small sample size, (range 7-125 patients) were largely retrospective in design, used a variety of RT treatment regimens and assessed functional outcomes using a variety of non-standardised instruments, making comparisons between studies very difficult. They commented that sexual function was particularly "poorly studied" but concluded that findings suggest pelvic RT has a negative impact on sexual function for both men and women (Temple et al. 2003). Of the five studies reviewed where sexual function was evaluated, only one 10 year old study included women who had received both surgery and radiotherapy for the management of their rectal cancer. Havenga et al. (1996) evaluated sexual function in a total of 54 women with rectal cancer, 21 had received adjuvant pre- or post-operative radiotherapy. Details presented in the review are scant but Temple et al. (2003) reported that 86% of the women were sexually active after surgery, with 85% having adequate vaginal lubrication and 91% of them able to achieve orgasm. These positive results are in stark contrast to more recent studies (Marijnen et al. 2005; Hendren et al. 2005) and there is no mention of the prevalence of loss of sexual desire or dyspareunia in this patient sample.

Furthermore, it would appear that the mere presence of sexual activity (again undefined for the purpose of this review) is taken to equate with satisfactory post-treatment sexual adjustment or recovery.

Mannaerts et al. (2001) explored the urological and sexual morbidity associated with multi-modal treatment (pre-operative RT, surgery and intra-operative RT) for both locally advanced and recurrent rectal cancer in male and female patients. Only the female data from patients with locally advanced rectal cancer is relevant to this review as those experiencing recurrent cancer have additional patient, disease and treatment related
factors that contribute to the development and manifestation of any sexual difficulties, making study comparisons difficult. Unfortunately, the authors combined both groups of women (both locally advanced and recurrent rectal cancer) in their analysis and it is not possible to consider the prevalence of sexual difficulties in the sub-set of women receiving primary treatment. However, when considering the sub-groups combined (n = 23 locally advanced, n = 25 locally recurrent) they found that 17/27 (63%) of women were interested in sexual activity pre-treatment compared to 7/27 (26%) after treatment (p = 0.002). The ability to have an orgasm was reduced from 16/22 (73%) pre-treatment to only 8/22 (36%) post-treatment (p = 0.008) and women also reported a reduced quality of orgasm (measured on a 5 cm visual analogue scale) from a mean score of 2.7 pre-treatment to 1.4 post-treatment (p = 0.000). Women were also asked if they experienced any discomfort or pain associated with intercourse and again a greater number of women reported pain following treatment, with 2/9 (22%) pre-treatment compared to 5/9 (56%) post-treatment. As only nine women answered this particular item no clear pattern of prevalence can be observed, nor is there any explanation as to why the response rate to this question was so poor (Mannaerts et al. 2001). In keeping with a number of other studies it was clear that these authors were noting combined morbidity, or what can be referred to as symptom clusters whereby the presence of more than one symptom, affecting more than one body system may interact and combine to create a more complex symptom experience for both the patient and the health professional conducting symptom assessment in clinical practice. For example, Mannaerts et al. (2001) found urological symptoms to be higher in the women in their study, with urinary urgency, frequency or incontinence likely to compound or exacerbate any sexual difficulties experienced. This would also be the case for women experiencing RT induced bowel symptoms, although Mannaerts et al. (2001) did not record this aspect of RT toxicity.

Accurate assessment of the frequency, nature, and causation of sexual difficulties in women being treated for rectal, bladder or anal cancer is complex, particularly when there are concurrent bladder and bowel symptoms that may impact on self-concept and sexual expression. Research personnel and validated instruments need to be capable of performing detailed, multi-faceted assessments that can begin to distinguish between direct and indirect treatment, illness, psychological and relationship factors that contribute to the prevalence, nature, clinical and personal significance or meaning of female sexual difficulties reported in such studies.
As can be seen from table 2.3, the majority of studies reviewed relating to this sub-group of women were retrospective and cross-sectional in design, with all of the bladder cancer studies and four of the rectal cancer studies recruiting either a small sample size overall or more importantly, a small sample of female participants, particularly those who had received pelvic RT.

Table 2.3: Summary of Non-Gynaecological Studies Addressing RT Induced Sexual Morbidity

<table>
<thead>
<tr>
<th>Summary of Studies Reviewed (n = 10)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary Diagnosis</strong></td>
</tr>
<tr>
<td>Bladder = 3 studies</td>
</tr>
<tr>
<td>Rectum = 6 studies</td>
</tr>
<tr>
<td>Anus = 1 study</td>
</tr>
<tr>
<td><strong>Design</strong></td>
</tr>
<tr>
<td>Cross-sectional / Retrospective = 6 studies</td>
</tr>
<tr>
<td>Case-control / Retrospective = 1 study</td>
</tr>
<tr>
<td>Longitudinal / Prospective = 3 studies</td>
</tr>
<tr>
<td>Age-matched controls included = 2 studies</td>
</tr>
<tr>
<td><strong>Sample Size</strong></td>
</tr>
<tr>
<td>Total Sample = 48 - 990 participants</td>
</tr>
<tr>
<td>Female sample = 7 - 179 women</td>
</tr>
<tr>
<td><strong>Instruments</strong></td>
</tr>
<tr>
<td>EORTC QLQ-CR38 = 4 studies</td>
</tr>
<tr>
<td>LENT SOMA = 1 study</td>
</tr>
<tr>
<td>Female Sexual Function Index (FSFI) = 1 study</td>
</tr>
<tr>
<td>Rotterdam Symptom Checklist (RSCL) = 1 study</td>
</tr>
<tr>
<td>Non-validated questionnaires = 5 studies</td>
</tr>
<tr>
<td>&gt; 1 instrument or added sexual function items = 3 studies</td>
</tr>
</tbody>
</table>

As in the review by Temple et al. (2003), a range of research instruments had been used to assess sexual function in this patient population, many of which were not specifically designed to elicit detailed information about female sexual difficulties. This particularly relates to instruments evaluating QOL where sexual function was only one small domain in an extensive questionnaire. In order to overcome this particular methodological weakness some researchers added specific sexual items to existing QOL or RT toxicity instruments (Marijnen et al, 2005) while others such as Hendren et al. (2005) combined a disease specific QOL tool (EORTC-QLQ-CR38) with a gender specific measure of sexual function (FSFI).

None of the studies included a definition of what was embraced by the terms sexual function or sexual dysfunction, with only three out of 10 studies providing detail of the specific types of sexual difficulties (loss of sexual interest, vaginal dryness,
dyspareunia, and orgasmic dysfunction) experienced by women post-treatment. The majority of studies appeared to define sexual activity as heterosexual intercourse and generally accepted such sexual expression as evidence of the lack of female sexual dysfunction or concerns. There were no qualitative studies encountered in the literature addressing this patient population, nor were there any studies where the impact on women's sexual partners or the couple relationship had been included in the study design. The combined methodological weaknesses of a small female sample size coupled with research instruments and analysis that lacked detail with regard to the precise nature of female sexual difficulties encountered has led to an inadequate evidence base for the assessment and subsequent management of sexual difficulties or concerns in women treated for these pelvic malignancies.

2.7 Conclusion

This chapter has reviewed the literature regarding female sexuality from the macro-context of the sociological and feminist literature, through professional and patient communication about sexual concerns in health care to the micro-context of the biomedical literature. It is clear that the majority of biomedical studies reviewed, considered the mainstay of evidence based practice for health professionals, fail to consider female sexual difficulties in their socio-cultural or relationship contexts. This biomedical literature takes no account of the influence that wider socio-historical perspectives have upon how female sexual difficulties are defined by both women and health professionals within the context of health and illness. Defining female sexual difficulties in a reductionist or functionalist manner has led to a construction of female sexuality that denies sexual expression for many older, disabled, single or lesbian women. This construction of female sexuality is not acknowledged by practitioners and thus remains unspoken and uncontested by the women encountered in the clinic. The dominant focus on achievement of vaginal intercourse as a measure of post-treatment sexual adjustment for women reinforces what some may consider restricted sexual goals for women recovering from pelvic cancer treatment (Hyde, 2007). Furthermore, continued failure to take account of the importance of the couple relationship and partner perspectives limits the focus of research and subsequent clinical assessment of female sexuality in oncology.
Table 2.4: Summary of Limitations in the Current Sexual Morbidity Evidence Base within Clinical Oncology

<table>
<thead>
<tr>
<th>Methodological Limitations</th>
<th>Research Focus Omissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retrospective not prospective data</td>
<td>Relationship &amp; partner factors rarely explored as context for sexual concerns</td>
</tr>
<tr>
<td>Cross-sectional not longitudinal design</td>
<td>No same sex partnerships</td>
</tr>
<tr>
<td>Survey design favoured, data often lacks depth of exploration</td>
<td>Limited cultural &amp; religious diversity</td>
</tr>
<tr>
<td>Few qualitative studies</td>
<td>Exclusion of women without a current partnership</td>
</tr>
<tr>
<td>Small, heterogeneous samples common</td>
<td>Lack of clear definition regarding what constitutes sexual activity</td>
</tr>
<tr>
<td>Research instruments often not validated</td>
<td>Studies defining female sexual expression normally equate this solely with heterosexual intercourse</td>
</tr>
<tr>
<td></td>
<td>Focus on sexual function or dysfunction as opposed to sexuality more broadly</td>
</tr>
<tr>
<td></td>
<td>Emotional &amp; relational dimensions of sexual expression often omitted or inadequately explored</td>
</tr>
<tr>
<td></td>
<td>Measurement of sexual (dys)function frequently omits relevant contextual factors</td>
</tr>
<tr>
<td></td>
<td>Physical examination findings (VE) rarely linked to sexual function parameters</td>
</tr>
</tbody>
</table>

As can be seen from table 2.4, the biomedical literature relied upon in clinical oncology has a number of methodological limitations and research focus omissions which restrict its utility for research and practice development in the psychosexual domain.

The medical and nursing literature reviewed in sections 2.4 to 2.6 take no account of the social and psychological factors that influence sexual expression, researching sexual dysfunction through the conceptual framework of logical positivism. In contrast, the sociological and feminist literature in sections 2.2 and 2.3 offer a radical critique of essentialist constructions of female sexual difficulties yet frequently lack a balanced interpretation or integration of research findings from the biomedical sciences. It is only in the healthcare communication research that there are limited degrees of paradigm integration in attempting to comprehend the inter- and intra-personal processes that complicate the discussion of sexual concerns in health care practice.

As will be discussed in chapter three, conducting a focused ethnography permits the exploration of female sexual health assessment within its social, psychological, biomedical and professional contexts. In studying female sexuality within an interpretive paradigm this
ethnography offers a detailed and more inclusive interpretation of the individual (personal) systemic and organisational perspectives that influence the clinical assessment and management of sexual difficulties following pelvic radiotherapy.
Chapter 3: Methodology and Research Method

3.1 Introduction

As can be seen from the domains of literature reviewed in chapter two, this research attempts to offer a synthesis of perspectives that embrace the multi-dimensional nature of the study of sexuality. Ethnography was chosen as the methodology for this research because the philosophy or paradigmatic view that underpins ethnography is congruent with the exploration of complex social phenomena, such as sexuality. Ethnography is capable of embracing multiple realities and perspectives on the nature and meaning of female sexuality after treatment for pelvic malignancies. Hence ethnography is also congruent with social constructionism as the underlying theoretical paradigm that informs the data analysis of this research.

In this chapter I explore ethnography from a theoretical perspective before identifying specific forms of ethnography that may be considered particularly useful to adopt in health care and nursing research. I discuss features of ethnographic methods of participant observation and in-depth interviews prior to consideration of the concept of reflexivity and the ethical dimensions of both the ethnographic research process and product: the ethnography itself. This chapter also addresses the challenges inherent to conducting research on sensitive topics (such as sexuality) with potentially vulnerable research participants (such as people affected by cancer). Following an outline of ethnographic data analysis approaches, triangulation and issues of rigour in ethnographic research this chapter concludes with a detailed account of research procedure. This latter section provides insights into the challenges associated with entering the field and experiencing the tensions inherent to overlapping and at times conflicting roles at the core of both my personal and professional identities.

3.2 Ethnography

Ethnography is located within the interpretive paradigm and can be defined variously as a research methodology, or a form of social research adherent to core characteristics or principles such as:
- a dominant emphasis on exploration of the nature of (often complex) social and cultural phenomena
- exploration with a small number of participants in considerable detail
- generation and subsequent analysis of relatively unstructured data
- data analysis that comprises interpretation of the meanings ascribed to human actions through written records of field (participant) observations, transcripts of structured talk (in-depth interviews) and textual (documentary) sources

(Hammersley & Atkinson 1995; Atkinson et al. 2002)

Researchers who use ethnography reject the notion of a single world view or objective reality in the social world, they contend that ethnography is solely a social construction that reflects the "...presuppositions and socio-historical circumstances of their production." (Hammersley & Atkinson, p.252, 1995).

The historical origins of ethnography lie in the disciplines of anthropology and sociology and it is only in recent times that ethnographic research has been adopted by nurse academics and sociologists to study nurses and nursing. Given its disciplinary origins, ethnography recognises the importance of studying human behaviour and social phenomena within the context of culture in its broadest sense, exploring in detail the taken for granted socio-cultural norms, values, rules and routines that shape social action and intent. For the purpose of this study, culture may be defined as "...the learned social behaviour or the way of life of a particular group of people." (Germain, 1993, p.237). Culture is a social construct comprising the concepts of setting or location, the peoples who occupy that setting both permanently and temporarily, and their shared characteristics and social purpose. The hospital is a sociocultural organisation that comprises a number of sub-cultures related to its physical and social structure, staff and user groups and organisational purpose. A culture is defined and experienced through its shared beliefs, values, norms, behaviours, language, interactions and rituals, together with the structural and functional elements that collectively define its purpose, aim or goal (Germain, 1993).

Defining a study as ethnographic is dependent not only on the methods used (predominantly participant observation, in-depth interviews and documentary analysis) but the type of research questions posed and how findings elicited are analysed (Skeggs, 2002). Ethnography frequently adopts a multi-method or mixed method approach to explore social phenomena in context. Nursing and healthcare research also frequently uses a combination of research methods within a single study to explore a health or illness
phenomenon, particularly when that concept or phenomenon is both multi-faceted and complex, as in the case of female sexuality in oncology. However, in providing a rationale for this decision many authors use the related terms of combination, mixing, integration and triangulation in a manner that lacks precision. Moran-Ellis et al. (2006) explored the rationale, processes and implications for using multiple methods within a single empirical investigation. In doing so they drew a distinction between the processes by which methods or data are brought into relationships with each other through combination, integration or mixing and the claims made for the epistemological status of the knowledge that emanate from such research. While the use of qualitative methodologies dominates, ethnographic research can also embrace more structured forms of data collection and analysis (Hammersley & Atkinson, 1995) as have been employed in this study.

Ethnography is always enmeshed in context and adopts a strategy of reflexivity to ensure the centrality of context in creating meaning for behaviours and utterances encountered in the field. Such reflexivity also takes account of influences emanating from both the researcher and research methods adopted (Savage, 2000).

Ethnography in health care embraces both emic and etic perspectives in producing an account of the culture or sub-culture under study. The emic (insider) perspective can be explored through data emanating from patients and health care professionals native to the research settings or contexts under study. While the nurse or health care ethnographer may themselves be an insider and be capable of representing an emic view, when studying settings or contexts that are unfamiliar to them they adopt the etic (or outsider) perspective. Findings emanating from one subculture or setting can not be readily applied to other settings even when they may appear superficially similar. While it is conceivable that the nurse ethnographer could offer both a legitimate emic and etic view of their role or an aspect of professional practice or behaviour, it would never be possible for them to offer an emic perspective on the experiences of patients or partners. Here the patient and partner remain the ‘experts’ on the experience of their illness, treatment and care (Holloway & Wheeler, 2002).

It is therefore imperative that ethnographers holding experience and knowledge of the research setting under study use reflexivity to maintain their openness and responsiveness to data that emerges from informants and the field as opposed to being based on prior professional or personal assumptions. The etic view remains relevant but is confined to application of theoretical constructs and interpretations of directly observed verbal
utterances or behaviours. The concept of reflexivity will be discussed further in section 3.8.1.

3.2.1 Ethnographic Research in Health Care
According to Bloor (2002) ethnography has been used to study health and medicine from as early as the 1950s and typically these studies may be grouped into four broad themes:

- Symbolic interactions in medical institutions
- Socially constructed character of professional medical categories
- Experience of illness and the sociology of the body
- Contemporary challenges facing medical ethnography

Most of these studies have been undertaken in health care settings with a focus on the training and clinical decision-making of doctors, on patient behaviours and on the nature and context of inter-professional relationships and communication.

There are a number of notable nurse ethnographers emanating from America, namely Janice Morse and Madeline Leininger, together with Jocelyn Lawler and Annette Street from Australia (Leininger, 1970; Morse, 1989; Lawler, 1991; Street, 1992). In the UK the work of Kath Melia has contributed to our understanding of how nursing students enter the world of nursing work (Melia, 1982), Jan Savage has explored the concept of nursing intimacy in patient-nurse communication (1995) and Helen Allan has explored the management of emotions in the infertility clinic from a psychoanalytical perspective (1999). Ethnography has also been used to explore elements of the adult oncology unit such as systems of social relations that influence health care professional and patient behaviours (Germain, 1979) or Wiseman's (2007) study of the nature of empathy on an oncology ward.

Ethnography may be particularly useful in health care research when attempting to access the beliefs, values and practices of professionals or patients that shape their experience of health care delivery and of illness itself. In this era of patient centred agenda setting within the National Health Service (NHS) in general, and the implementation and evaluation of the cancer plan more specifically (DH, 2000), ethnography can assist the discovery of "ethnocentric assumptions" emanating from professionals and policy makers that may act as barriers to the provision of culturally responsive services (Savage, 2000). Ethnography can also be useful in studying complex and multi-faceted change processes, thus leading to a greater understanding of why organisational change in large organisations like the
NHS can prove to be so challenging. More specifically, ethnographic research in health care can:

"...identify the ways an organisation's formal structure (its rules and decision making hierarchies) are influenced by an informal system created by individuals or groups within the organisation or indicate how professional knowledge is locally produced in particular settings."

(Savage, 2000 p.1402).

3.2.2 Critical and Feminist Ethnography

Some authors make the distinction between descriptive (conventional) ethnography and what is termed critical ethnography, often conducted by researchers operating within the paradigm of critical theory (Holloway & Wheeler, 2002). Critical ethnography goes beyond description of social or cultural phenomena to study the socio-political factors, power dynamics and constructs that serve to promote the domination of certain groups, behaviours and ideologies within society and its institutions, while maintaining the oppression or marginalisation of others.

Critical ethnography is therefore more political in intent, seeking to influence or shape the status quo as opposed to merely describing and understanding it, leading to what some may consider emancipation through illumination. This politicised stance and desire to influence dominant social norms / mores through research endeavours is, as we shall read later in this section, also a central tenet of feminist research, or research that is informed by feminist ideology. The underlying aims of both critical ethnography and feminist research are congruent with the use of ethnography in nursing / health care research in that researchers are concerned with patient partnership and empowerment as well as harbouring a strong desire to change clinical practice as opposed to merely observing and commenting upon it (Savage, 2000). Hence critical ethnography can be used to highlight perspectives that are largely silent or marginalised in main (male)stream thinking about the subject of sexuality in cancer care.

Although feminist ethnography also emanated from the disciplines of anthropology and sociology, more recently it has been used to illuminate the theory and practice of nursing work and of nurses as women, together with their contribution to the experiences of women as patients or recipients of health care. Feminist researchers of the 1970s sought research methods most suitable for the detailed study of women's lives, but more recently there has been a shift from ethnographic research focusing on women to ethnographies that are informed by feminist theory and perspectives (Allan, 1999; Skeggs, 2002). Feminism and ethnography share core concepts such as participation, experience,
social construction of action and meaning, the importance of context and subjectivity (Skeggs, 2002). Feminist ethnography maintains the political gaze of feminism in co-constructing accounts of the experiences and lives of women through the observation, documentation and interpretation of women (and men's) voices. Thus feminist ethnography offers insights from the study of women's lives and experiences that were tacit, ignored or marginal to core health care knowledge and practice. Such knowledge has the capacity to influence and shape contemporary health care roles and service developments that contribute to the well-being of both women and men in society.

3.2.3 Focused Ethnography

The ethnographic tradition is normally associated with protracted immersion in the field. This can be a source of difficulty for nursing research, particularly in the context of time limited research contracts and scarce sources of research sponsorship. As Savage (1995) laments, the majority of ethnographies conducted within the discipline of nursing take place over a relatively short time frame, sometimes referred to as a mini-ethnography or a study that can be said to have adopted an ethnographic approach as opposed to true ethnography. Morse and Field (1996) refer to the concept of the focused ethnography, a type of ethnography used increasingly in the study of health care services and their subcultures. Focused ethnographies explore naturally occurring phenomena in context, but do so in a more delineated and time-limited manner. A focused ethnography is frequently used to influence clinical practice and differs in a number of important ways from the classical ethnography of anthropology or sociology (Morse & Field, 1996). These differences can be summarized as:

- The research topic is selected before commencement of data collection as opposed to emerging during data collection and analysis
- Participants are linked by a common site, but this location may be a clinical setting (such as a follow up clinic) rather than a place of residence
- Participants may not be connected by the same culture, in its broadest sense, but share behavioural norms and a common language emanating from their shared experience of an illness
- Participant observation is limited to specific activities and time frames
- Interviews are limited to the selected topic and surrounding event(s)

(Mueke, 1994)
To date, female sexuality both generally and within the context of cancer treatment has not been explored as thoroughly as that of its male counterpart. This current ethnography aims to raise professional awareness and to influence future health care practice and service provision in relation to women's sexual recovery in oncology. In its research design, conduct, analysis and interpretation, and dissemination of findings this study is informed by the ideology and principles of both critical and feminist ethnography. The views of women who have experienced the sexual consequences of cancer treatment on their sexuality and sexual expression are central to this research. However, also central to the findings of this research is an understanding of women's sexual recovery within the context of their relationships with the men in their lives. Hence, the voices of men as both partners and health professionals, involved in these women's lives, are also incorporated in this study as they offer important perspectives on the ways in which women and men collectively shape the sexual lives of women and couples after cancer treatment.

The research topic and associated research questions were clearly delineated from this study's inception and this ethnography collected data over a relatively short time period (September 2005 to September 2006). Hence this study adheres to the philosophy of critical and feminist ethnographies, adopts the principles of ethnographic research practice and can thus be considered a focused ethnography as defined by Mueke (1994).

3.3 Ethnographic Methods: participant observation

Participant observation is seen by many as the defining data collection method in ethnographic research. Typically participant observation involves protracted immersion in the field whereby the ethnographer shares the social and cultural world of research participants. The relationship between researcher and participant is seen as reciprocal and by some perhaps even egalitarian in nature, whereas for other ethnographers there is recognition of the inherent power dynamic in who determines the direction of the research gaze in fulfilment of pre-determined research objectives (Hammersley & Atkinson, 1995).

Communication of the concepts and perspectives gained through participant observation involves a process of translation from what has been observed to written text or field notes that can be subjected to analysis and interpretation by those outside the immediate research field, actors and action (Spradley, 1980). Ethnographers continue to address the shifts in meaning and potential reduction in authenticity that can result from
the 'translation' of field notes into a finished ethnographic account or thesis (Emerson et al. 2002). Closer scrutiny reveals multiple steps in this 'inscription' process, from initial notes made in the field, to more elaborate field notes developed once the ethnographer has left the field, to the production of a text for the completed ethnography. At each stage the potential for loss of or alteration in meaning is present and must be something researchers pay due attention towards restricting. Strategies that can be used to both minimise and account for such altered meaning will be addressed more fully in the section 3.8.1 regarding reflexivity and research rigour in ethnography.

Emerson et al. (2002) view field notes as a form of representation where the researcher turns what may be a fleeting event into a textual account that can be consulted, analysed and interpreted on more than one occasion. Field notes serve to reduce complexity and "reconstitute the [social] world in preserved forms that can be reviewed, studied and thought about time and time again" (p.353).

It is inevitable that field notes are a highly selective form of data, their content and focus determined by the philosophical and disciplinary frame of reference of the researcher and specific research question(s) posed as much as the nature and magnitude of what is taking place within the field (Emerson et al. 2002). The focus of this research shaped and directed my gaze during participant observation so that certain clinician and patient behaviours were recorded undoubtedly at the expense of others considered more marginal to the research task. I also used field notes to reflect on thoughts and feelings that occurred during the process of observation and to pose questions to myself regarding the behaviours and practices I witnessed and the extent to which they were situated within familiar or unfamiliar professional or personal territory.

Field notes may adopt a number of different literary styles (see Van Maanen 1988: realist, confessional and impressionist tales) and can include textual data that captures not only what has been observed but also the researcher's thoughts, reactions and preliminary interpretations. In contrast, Emerson et al. (2002) suggest field notes should be restricted to documenting observed behaviours and events, with researcher analyses kept separate in the form of a field diary or journal. It is certainly important to ensure field notes are sufficiently transparent so that one can readily make the distinction between researcher and participant perspectives.
3.4 Ethnographic Interviews

The characteristics of ethnographic interviewing arise from the nature of the relationship forged between research participants and the ethnographer who normally spends time establishing what is referred to as:

“...respectful, on-going relationships with their interviewees, including enough rapport for there to be a genuine exchange of views and enough time and openness in the interviews for the interviewees to explore purposefully with the researcher the meanings they place on events in their worlds”. (Heyl, 2002 p.369)

It is the quality of the developing and 'on-going' relationship between participant and researcher that sets this type of interview apart from other types of interview adopted in social science research. It therefore follows a criticism of the adoption of a brief or 'mini' ethnographic approach, or the restriction of participant contact to a single interview, is that this may serve to undermine the degree of openness and disclosure achieved within the interview context. I believe it is important to adhere to the principles that underpin ethnographic interviewing (see Table 3.1) thus maximising the likelihood that participants will disclose sensitive and personal information when sufficient rapport and support is created within the research relationship, even if it is of limited duration. Furthermore, I would contend that there is evidence in the nature of the data generated through in-depth interviews with patients in this study that high levels of disclosure can be achieved within single interviews. The willingness of women to disclose sensitive information about sexuality, within the context of a single research interview, can be accounted for by the use of my skills as a psychosexual therapist.

Table 3.1: Principles in the Conduct of Ethnographic Interviews (Heyl, 2002: 370)

<table>
<thead>
<tr>
<th>Principle</th>
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<tbody>
<tr>
<td>Listen well and respectfully, developing an ethical engagement with the participants at all stages of the project</td>
</tr>
<tr>
<td>Acquire a self awareness of our role in the co-construction of meaning during the interview process</td>
</tr>
<tr>
<td>Be cognizant of ways in which both the ongoing relationship and the broader social context affect participants, the interview process and the project outcomes</td>
</tr>
<tr>
<td>Recognise that dialogue is discovery and only partial knowledge will ever be attained</td>
</tr>
</tbody>
</table>

81
Central to both ethnography and feminist approaches to research is the recognition that interviewing constitutes a complex form of social interaction and talk whereby the data generated is co-constructed by that interactive process, before being reconstructed through the processes of analysis, interpretation and subsequent selective presentation in the final ethnographic account (Heyl, 2002). This co-construction of knowledge and meaning is sometimes referred to as an 'active' interview whereby attention is paid not only to the content of interview talk but the relationship between content, how responses are created (or avoided) and what circumstances determine the nature and content of responses, become part of the interpretative process (Holstein & Gubrium, 1995:79).

While feminists argue the aim of such interviews is to capture the most authentic information or accounts with regard to the focus of the study, through the development of empathic and equal relationships with women, it is also important to recognise the potential for emotional discomfort or more subtle forms of coercion or exploitation inherent to this 'up close and personal' style (Stacey, 1988). These issues are discussed further in the next section entitled Ethical Dimensions of Ethnography.

3.5 Ethical Dimensions of Ethnography

Inevitably the ethical dimensions inherent to the conduct of ethnographic research are determined by assumptions ethnographers make about reality and the responsibilities each researcher has to the generation or construction of knowledge that is true to the multiple realities they encounter in their research journey. Nurses who use ethnography are influenced by the same philosophical frames of reference (deontological versus consequentialist) and ethical principles (beneficence, non-maleficence, autonomy and justice) that guide ethical decision making and behaviour in both the research and clinical domains of British health care practice.

Those who commend the virtues of critical ethnography and feminist research as research approaches that are “emancipatory”, or have the principle goal of “consciousness-raising” for a marginal or oppressed group or concept, could legitimately be accused of arrogance and “ paternalism / maternalism” in assuming that such individuals, groups or concepts always benefit from the increased self and / or outsider knowledge that emanates from such research endeavours (Murphy & Dingwall, 2002).
Feminist ethnographers have considered the power relations inherent to the dynamic between the researcher and researched and have come to the conclusion that a perceived or actual power imbalance does not automatically have to lead to exploitation (Wolf, 1996). Typically, feminist researchers address such inherent power imbalance by adopting a more "...intimate, authentic and sisterly..." relationship with research participants (Murphy & Dingwall, 2002). However, it is imperative that the development of closer relationships does not lead to a more subtle form of oppression or manipulation for participants. It is for this and other reasons that researcher reflexivity and supervision relationships are important to the development of self-awareness and the identification, negotiation and maintenance of appropriate researcher-participant boundaries.

Ethnographic research requires the development of close and interactive relationships with research participants in an endeavour to capture data that is an accurate and detailed exploration of a complex, multi-faceted concept within its social and cultural context. The very nature of such relationships may be more likely to lead to a tendency towards participant (or researcher) disclosure of issues that may hold special meaning or particular sensitivity within their lives. In making such a disclosure the participant has to trust that the researcher will treat their words with understanding and respect not just at the time of data collection but in the recording of data and its subsequent interpretation and representation within an ethnographic account (Hammersley & Atkinson, 1995).

In-depth interviews and participant observation are both methods that lend themselves to deeper exploration of the chosen research topic. Sensitive topics such as female sexuality, sexual expression and sexual rehabilitation, particularly when framed within the context of serious illness, may increase the likelihood that participants experience discomfort in their self-consciousness, anxiety or embarrassment through the processes of participant observation or through disclosure during ethnographic interviews (Murphy & Dingwall, 2002). While the ethnographer may not intend to cause embarrassment or distress, the emotions and insights that may be generated through in-depth interviewing are to a large extent unpredictable. Mishler (1986) offers a framework of empowerment in working with interview respondents that identifies three types of prevailing relationships: informants and reporters, research collaborators and learners/actors and advocates. Within this ethnography I endeavoured to work with study participants as research collaborators. This is congruent with both feminist research philosophy and my personal belief that the women, partners and health professionals who contributed to this study all brought a unique perspective to the multi-faceted topic of this
research. Hence this study offered each one of us an opportunity to share that perspective in co-constructing the nature and meaning of female sexuality after cancer treatment.

Unlike other methodologies, health care research that takes place in uncontrolled clinical settings and which regards data gained through participant observation as central to the conceptual understanding of a given phenomenon, have virtually no control over those who enter the research field and thus come under the researcher's gaze. Clearly this has ramifications for processes of consent, whether actively sought or implied, and the ability to provide unwitting participants with the information that may be necessary for them to determine whether or not they wish to remain in the setting where such observation is taking place. Within the context of this study, patients taking part in medical follow-up consultations, accompanying partners and the medical staff conducting such clinics were the central actors (Spradley, 1980) in this research environment. However, it was not uncommon for other health professionals (nurses, doctors, therapy radiographers, reception and support staff) to unwittingly enter the field and contribute to the data generated on that occasion. Thus informed consent was negotiated and regularly re-confirmed with research participants (Savage, 2000).

The ethical promise of maintaining participant anonymity and preservation of confidentiality in the study of topics such as sexuality underpins both the participant's decision to take part in research endeavours and their willingness to make personal and potentially sensitive disclosures. However, the very nature of ethnographic studies requires researchers to maintain detailed field notes and interview transcripts that may contain sufficient detail to make individuals and settings identifiable. In this study, steps were taken to ensure that raw data and associated participant consent forms were held securely with access restricted to the chief investigator and immediate research supervision team. Following initial reading of transcripts and verification of their accuracy, identifying details were removed from verbatim accounts and substituted with appropriate descriptors or pseudonyms. Field notes were expanded and retained with contextual and personnel details altered (codified) to mask the true identity of both settings and individuals.

However, it would be naïve to imagine that such steps guarantee preservation of anonymity, as the mere presence of a known or identifiable researcher in the field may be sufficient to enable insiders and some outsiders to identify data sources after publication.
Dependent on the context and content of data extracts, personal unmasking by participants may lead to private embarrassment or regret even where there are no external ramifications (Murphy & Dingwall, 2002). Such personal identification with data extracts may be made more difficult for participants when accompanied by researcher interpretations that ignore and thus challenge the unique defences and coping strategies adopted by participants to manage past distress or embarrassment. At least within the context of observation, or interviews where interactions indicated distress, the researcher can adopt an active stance in providing sensitive and appropriate support for the participant and direct them to relevant personal or professional resources according to their perceived need(s).

The first ethical challenge in writing ethnography lies in the capacity of the researcher to provide accurate interpretations of the data, while taking care to use language skilfully to represent the social realities encountered and captured through the nature and context of observations and interactions in the field (Van Maanen, 1988). Issues of confidentiality are relevant to all stages of the ethnographic research process, but may be of particular concern at the point of publication of an ethnographic account in a thesis, or more likely in an institutional report or journal article. As most ethnographic research is carried out within a particular context, and incorporates a relatively small number of participants, it is more challenging to ensure that the research context and its inhabitants are kept anonymous. This is particularly so in the production of accounts for specific audiences, such as a funding body or research site report. While the goal of effective ethnographic writing should be an authentic representation of the participant's truths and realities, such authenticity may also lead to a breach of confidentiality if colleagues or managers recognise the identities contained within such an account.

3.5.1 Conducting Research on Sensitive Topics and with Vulnerable Populations

Sensitive research can be classified as that which “...potentially poses a substantial threat to those who are or have been involved in it.” (Gibson, 1996 p.65). This study could be said to be inherently sensitive from both a topic and participant perspective, in that it involves exploring aspects of intimacy and sexual recovery and did so in a population of women who have experienced cancer and its treatment at a time in their illness trajectory when their future survival remained uncertain (Cannon, 1989).
Awareness of the sensitivity of this research began for me at the point of research topic definition and study design and evolved as I negotiated ethical approval, research site access and began participant observation and in-depth interviews with study participants. This sensitivity was emphasised and defined perhaps more by those I met in the development and conduct of my study than it was by me. This apparent incongruence may be explained, at least in part, by my dual professional identity as a cancer nurse and psychosexual therapist whereby the regular detailed discussion of sexual issues was familiar practice territory for me. This was in stark contrast to many professional nursing and medical colleagues on the ethics committee and in the oncology practice setting. Lee (1993) categorises the potential threats in sensitive research as being:

- Intrusive Threat
- Threat of sanction
- Political Threat
- Threat to the Researcher

Within this study the main concern related to the perceived intrusive threat for patients, their partners and the health professionals asked to discuss what are often perceived as private or personal issues pertinent to the focus of this study. A recent grounded theory study by Dickson-Swift et al. (2006) explored the experiences of 30 health researchers conducting qualitative research in sensitive topics. They found that even those who had a professional background in health care had difficulty in managing the emotional involvement inherent to building effective rapport with participants for the purposes of in-depth interviewing. For many there was also a tension between distancing tactics they may have employed in their health professional role, versus the philosophical stance and research process expectations of feminist methodology (Dickson-Swift, 2006). While researchers were aware of their ethical responsibilities to debrief respondents regarding the complex feelings that participation in such research can create, many of them did not feel adequately trained for such a role. Dickson-Swift (2006) identified the need for greater awareness at the research design stage of the challenges involved in managing boundaries in sensitive research and recommended the development of guidance around:

- Researcher disclosure
- Researcher – Participant Rapport Development
- Clarity in the boundary between research and therapy
Strategies for leaving the research relationship
Management of professional boundaries

I will return to many of these points later in this chapter (section 3.5.3) in discussing the challenges of role boundary negotiation and role expectations in fieldwork.

There may also be a perceived threat to the researcher's professional reputation as a nurse by virtue of her perceived enthusiasm and comfort in discussing sexual issues with a range of participants. This potential threat emanates from the persistent tendency for female nurses to be stereotyped as sexually permissive, or for nursing to be seen as a metaphor for sex (see section 2.4.2). This enduring stereotype has been explored from a variety of perspectives (Lawler 1991, Porter 1992) and appears to emanate from the association of nursing work with the need for intimate physical contact with people's bodies (White, 2002). Within the context of this study and my role as a clinical researcher studying sexuality I took care to set and maintain appropriate boundaries and demeanour with research participants and clinical and research colleagues, co-investigators and collaborators.

Ethical approval for studies involving vulnerable populations and sensitive topics can be difficult to obtain (Gibson, 1996). The ethics committee that approved this study appeared largely comfortable with the steps taken at the research design stage to protect the well-being of interview participants. However, they did suggest a number of additional safeguards in relation to the maintenance of privacy and dignity in the context of participant observation of medical follow-up clinics where intimate physical examinations were an integral element of the clinic process. These steps are discussed in detail later in this chapter (section 3.5.3).

Formal ethics approval (COREC) also takes account of the potential for any physical or psychological harm to befall the researcher and asks that the chief investigator outlines relevant safeguards in the research procedure to this end. I indicated that I would have access to both research and clinical supervision where the impact of listening to the stories of women and their partners about their sexual concerns could be discussed and my emotional response explored and contained.

There were times during data collection where I experienced great difficulty in maintaining a balanced or more marginal role as a researcher. During participant observation it was not uncommon for me to be present when distressing news was broken to patients, often related to recurrent or advanced disease that would reduce the woman's hope for cure or
shorten her life expectancy. If I had adopted a pure nursing response to this distress I would have become fully participative and perhaps lost the ability to also observe the necessary elements of such an interaction for research purposes. Arber (2006) recalled her responses to a dilemma in managing her dual identities as researcher and practitioner when witnessing the emotional distress of relatives after they received bad news during her fieldwork in a hospice setting. She was torn between her role as a nurse and that of maintaining distance as a researcher. This tension may be felt particularly when no nurse is present to intervene to provide a supportive response in the presence of overt distress. During research interviews with women in their own homes I did not have recourse to clinical colleagues and felt I had a professional and ethical responsibility to support a woman should she become distressed either during or following completion of the recording of our interview together. Even in the hospital setting, where most of the interviews took place, it was rarely possible to seek the assistance of a colleague as they were busy with their own clinical work and I felt they would not have appreciated me asking them to intervene to provide support for a woman in whom I had created difficulty or distress. Through the rapport created at the time of the research interviews women frequently disclosed their ongoing fears and anxieties about surviving the experience of cancer and talked at length about the uncertainties and emotional impact of going through treatment (Cannon, 1989; Macmillan, 2006). Many of the women commented on the fact that it was unusual for them to have the opportunity to talk about the emotions and feelings associated with their experience of cancer and its treatment. This may explain why it was not uncommon for me to be present in some women's homes for up to three hours, despite the recorded interview lasting less than one hour. Most of the women subsequently stated that they had found the interview experience helpful from an emotional perspective and some women had also been able to gain further information about their sexual recovery (Colbourne & Sque, 2005). It appeared to me that despite the policy drive from the Department of Health advocating improvements in the psychosocial support and emotional care for people affected by cancer (NICE 2004a), these women's recent experiences of cancer services suggested that in reality the provision of emotional care often remains at the level of professional rhetoric (Macmillan, 2006).

It is unusual for ethics committees to consider the impact of sensitive research on the wider research team such as transcribers, supervisors and examiners (McClosker et al. 2001). I had discussed with my supervision team the rationale for employing a person

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to assist me with transcribing the qualitative interview data. We discussed the potential psychological impact of listening to women describe their experiences and feelings about cancer treatment and their sexual recovery on someone without prior exposure to this sort of data. The content of interview transcripts from a study such as this varies considerably in the extent to which emotional distress, expressions of anger or other negative emotions are present. As a research team we felt that it was important to engage a transcriber who had a professional health or psychology background and would thus be more familiar with what these women were describing. I employed the services of a psychology research colleague to act in this capacity. This also meant that I could extend the maintenance of confidentiality to the transcriber as she would be bound by her adherence to research ethics and research governance principles (McClosker et al. 2001).

During the early period of transcribing my colleague and I would often discuss her thoughts and feelings following completion of particular recordings. It seemed important to her to know some details of the interviewee in order to make sense of what she had heard during the transcription process and to be able to manage her impressions. While the identity of the participants was not disclosed to the transcriber I did share some information about the interview process and thoughts about my interaction with the participant. This appeared to serve as a type of supervision and support mechanism for my colleague and so we agreed that this would remain an informal process throughout the period of transcription. McClosker et al. (2001) challenge the common assumption that the transcriber is merely a neutral and unaffected extension of the recording apparatus. Instead they remind us that transcribers are a "...human participant in the research process..." and recommend appropriate briefing and debriefing where they are working with sensitive data (McClosker et al. 2001, para 5.3).

Where there was a particularly high level of emotional content in the interview I made my colleague aware of this in advance of her beginning transcription. She also commented on the fact that she was more likely to take regular breaks and pace completion of such an interview where she found herself reacting to the interview content.

My supervisors are both experienced nurse researchers and academics with clinical backgrounds in cancer care, acute care and women's health. Hence they were familiar with the emotional responses engendered in conducting sensitive research in healthcare for all study participants. Academic supervision was structured in such a way that my emotional engagement with the fieldwork, both participant observation in the clinic and
patient or partner interviews, could be explored and interpreted in such a way that this in turn became a rich source of additional insights through reflexivity.

Clearly there are a number of methodological considerations in conducting research on sensitive topics, not least the effect this may have on the willingness of relevant or representative individuals to take part in such a study (Gibson, 1996). Where the study population is deemed to be rare, deviant or hidden, researchers may have to adopt specific sampling approaches, such as snowball design, to access a diverse sample of participants (Platzer & James, 1997). While women who have completed pelvic radiotherapy for treatment of a pelvic malignancy are not an elusive population in the same way as gay and lesbian patients may be considered "hidden" (Platzer & James, 1997) their experience of the sexual consequences of treatment has remained largely elusive and unexplored within mainstream medicine and nursing. Selection bias is an inevitable feature of research in sexuality and in this study will be accounted for in the analysis and interpretation of results and through researcher reflexivity.

Concerns may also be expressed in relation to the validity and reliability of research findings where there is a possibility that participant discomfort or embarrassment may lead them to withhold the truth of their experiences. Researchers may therefore adopt strategies in their research design to increase the likelihood that the topic under study is adequately and accurately explored (Gibson, 1996). Adopting feminist research principles in the conduct of research interviews with women participating in this study may have encouraged a more honest and extensive disclosure of sensitive experiences than would otherwise have been expected (Dickson-Swift et al. 2006). In this study validity was also enhanced through the incorporation of multiple perspectives, leading to triangulation of data or at least to exploration of the phenomena under study from a range of perspectives thereby increasing the truth value of the data generated.

3.5.2 Ethical Dimensions of Gaining and Maintaining Access
As discussed in the preceding section, the ethical dimensions of conducting an ethnographic study are more a process or thread of awareness and moral action that begin at the design stage of a study and are re-visited, re-shaped and evolve as the study progresses; perhaps only coming to a conclusion when the final ethnography has been
written and presented to its principal audiences. While formal ethical approval aspects of the study are presented here, ethical issues arising during the conduct of the study will be addressed throughout other relevant sections of the thesis.

In accordance with the European Directive (EU2001/20/EC) this qualitative, multi-site health-related study was submitted to a central NHS research ethics office (Central Office of Research Ethics Committees) for formal review by a Main Research Ethics Committee (MREC: Appendix 1). In addition to this over-arching ethical scrutiny, local research ethics committees (LREC) at each of the proposed NHS Trusts conducted a site specific assessment of the research to ensure its feasibility on ethical grounds at the proposed clinical research site (Appendix 2). Following participation in an ethics committee meeting (May 2005) and the submission of minor amendments, final MREC approval for the study to proceed was made in June 2005. Ethical approval from the University of Surrey Ethics Committee was granted in July 2005 (Appendix 3).

From a research governance perspective, managerial approval to conduct the research was achieved through submission of the research protocol and Trust specific documentation to two Trust research and development (R&D) committees and approval granted in Trust research site A in April 2005 and July 2005 in site B (Appendix 4). Honorary contracts were also obtained (Site A September 2005, Site B May 2005) prior to being granted access to patient data for study sampling purposes and for the purpose of approving direct patient contact in the participant observation and interview elements of the study.

In accordance with site specific Trust requirements at site A, a consultant clinical oncologist was named as a principal investigator responsible for the conduct of the study at that research site while site B nominated me to be the named principal investigator as well as being the chief investigator with overall responsibility for the study conduct as defined by COREC (2004).

3.5.3 Ethical Dimensions of Study Procedure: promoting participant and researcher safety

Due to the sensitive nature of this study ethical dimensions were addressed overtly from early stages of its development. Protection of vulnerable participants was promoted initially through the establishment of rigorous inclusion and exclusion criteria. During audit of electronic patient records, clinicians familiar with the patients being recruited were
consulted where there were any concerns about a patient’s suitability to be approached prior to any interview letter being sent.

Patients and partners who had agreed to participate in the study and who identified a need for further information about their medical management or experienced distress during or following the interview were offered the contact names of relevant members of their treatment team (normally the clinical nurse specialist (CNS) or medical consultant) to approach for further information, support and onward referral where deemed necessary. I acted as an additional resource for specialist information about routes of referral, for counselling services regarding sexual and relationship concerns and to give practical advice about specific sexual difficulties where requested.

As will be discussed later in this chapter, and in the study findings, there were times when it was necessary for me to use my awareness of patient / partner cues to identify potential distress in participants. At these times the role of researcher began to overlap with those of counsellor and clinician whereby I made decisions not to probe particular interview responses in order to minimise further distress (Dickson-Swift et al. 2006). At other times I acknowledged the distress within the interview, indicating we could return to a particular concern following cessation of the recording in order to provide support and guidance regarding management of an existing sexual or relationship difficulty. Such strategies clearly impact on the nature and depth of data generated, with the potential for reduced data quality if necessary probes are omitted. Equally, the overt acknowledgement of distress or concern expressed during an interview can create greater rapport with participants and lead to disclosure of responses that may otherwise be considered unacceptable by the participant (McClosker et al. 2001).

Another potential source of distress to participants that can be overlooked in the name of research rigour is that associated with the processes of participant validation. As will be evident from the data extracts in this thesis, these interview transcripts contain both sensitive and sexually explicit material that may not be appropriate to send to research participants by post where safe receipt, privacy and confidentiality cannot be guaranteed. Many of these women and their partners lived a considerable distance from the research site and so it was not considered feasible to return the transcripts and address participant validation in person. As the interviews had enabled substantial emotional disclosure and some distress I was also concerned that women and partners may become distressed while reading them at home some weeks / months later without ready access to appropriate support. Furthermore, from a theoretical (social constructionist) and
methodological perspective the data in these transcripts, while hopefully an authentic and credible representation of participant's accounts at the time of their interview, may no longer represent their current perception and context. Hence participant feedback on interview transcripts generated at an earlier point could be considered to constitute a new set of data as opposed to enhancing credibility of the original data. Principally it was for ethical reasons that I reached the decision not to undertake participant validation of interview transcripts. Measures to enhance research rigour in ethnographic research are discussed further in section 3.8.

The ethics committee appeared satisfied with the steps taken to ensure the support and well-being of patient and partner interview participants but had some additional recommendations to make in relation to issues of consent and the maintenance of privacy and dignity associated with the participant observation elements of the study. A brief information sheet (Appendix 5) about the study was compiled to distribute to patients in the waiting area, prior to entering the consulting room. This strategy was to ensure patients had time to consider whether or not they wished to have a researcher present during their medical consultation. As it was nurses who managed the flow of patients through the clinics I liaised with them on an ongoing basis to ensure that timely distribution to patients took place while I was present in the clinic suite engaged in participant observation. However, I was aware that due to the busyness of the clinics and the complexity of patient and doctor movements within the clinic there were occasions when information sheets were omitted. Verbal consent for me to be present at the patient's consultation was still sought on every occasion and an information sheet given where it was identified this had not been made available.

As it was important to observe naturally occurring talk and normal practice during consultations, the specific topic of the study remained covert in order not to influence patient led communication or agenda setting. Patients were informed that:

"This information sheet is to make you aware that there is a research study taking place in this outpatient clinic that aims to explore the content of doctor-patient discussions that take place during radiotherapy follow-up clinics."

Medical staff conducting follow-up were, however, aware of the topic of my study in advance of granting me permission to be present. There were no refusals from patients,
doctors or nurses during any of the observed consultations. However, there were a small number of occasions when I removed myself before or during the consultation where I considered it inappropriate or insensitive for me to remain, for example when bad news was being broken and the high level of emotional distress in the room suggested a need for additional privacy to maintain patient dignity.

The brief patient information sheet (Appendix 5) stated clear boundaries for my role as a researcher in the field, emphasising that:

"...she [researcher] will not take part in the consultation as she is there in a research observation capacity only."

Patients were also informed that I would not be present during any intimate physical examination, thus protecting patient's privacy in the clinical context.

"...she [researcher] will not be present during this [intimate] examination and your privacy will be maintained."

In reality the construction of the physical environment and associated clinic process made the operationalisation of this ethical guidance in practice quite difficult. As a researcher I had to consider how the ethics committee (MREC) defined or constructed the concept of privacy in the context of this clinical setting.

Within each consultation room there was an area where the examination couch was placed and curtains could be drawn to separate the couch from the rest of that enclosed space. The doctor conducting the consultation normally moved from discussion to physical examination in a seamless manner, creating a dilemma for me in relation to what constituted “being present”. Intimate examinations took place both in the presence and at times in the absence of a chaperone and so at times there was no opportunity to leave the environment in an unobtrusive manner. In my field notes I questioned as to whether or not the division of a space by curtains created sufficient privacy as to constitute “not being present” during women's physical examinations? The closing of curtains to create an enclosed and private space is a common strategy within clinical environments where it is impossible to have solid barriers such as walls or partitions separating patients or specific activities.

In the context of the clinic I was left wondering whether or not I had truly vacated the woman's private space by being on the other side of closed curtains or did I merely...
mask my covert participation in her examination as I could hear what was being discussed during the examination.

To have left the room entirely would have created a process difficulty for the doctor and myself in that the smooth transitions between discussion and clinical examination would have to be disrupted as I was requested to enter and leave the room. There was also a chance that in a busy clinic environment doctors would forget to invite me to rejoin them for the remaining portion of the consultation, thus excluding me from observing potentially valuable data.

As will be discussed in the findings chapters and in relation to research reflexivity, maintenance of such firm boundaries created role tension as it could also be argued that maintaining spatial distance is in direct contradiction to both the research role expectations of a participant observer and adherence to feminist research principles aimed at promoting reciprocity with women as participants in research (Dickson-Swift et al. 2006). Hence I encountered role ambiguity and role tension as I attempted to adhere to the guidance of the ethics committee in maintaining firm emotional, behavioural and spatial boundaries while in the field. I began to experience both personal and professional dissonance regarding the practice expectations inherent to my presence in the clinic as an experienced female cancer nurse. In the conduct of this study I fulfilled a number of overlapping and at times conflicting roles; some were core elements of my professional and personal identity while others were projected onto me by colleagues or patients in the context of the clinic. Such role “re-constructions” that emerge through the processes of ethnography are discussed in some detail by Day (2002) and are summarised in Figure 3.1. The ethical dilemmas I experienced in negotiating these multiple identities or “personal and professional re-constructions” were:

- **Researcher as outsider versus insider** between different health professional participants and between different research settings
- **Researcher** versus **Practitioner** (Cancer Nurse) when invited to act as chaperone by male medical staff for intimate physical examinations in the absence of a clinic nurse
- **Researcher** versus **Practitioner** (Cancer Nurse) when asked to assist in routine clinic activities by one female consultant when the clinic nurse not available
• **Practitioner** (Cancer Nurse) versus **Researcher** in considering the emotional and practical effect of delay or absence of a chaperone on women undergoing vaginal or rectal examination and on the clinic process

• **Researcher** versus **Practitioner** (Cancer Nurse & Psychosexual Therapist) in my desire to minimise influence on naturally occurring behaviours observed in the clinic when asked by medical colleagues to provide a clinical service to women who had an expressed need in relation to their sexual recovery

**Figure 3.1: Researcher Role Re-Constructions in the Field / Clinic**

I experienced fieldwork as a fascinating, enjoyable yet stressful activity where I was required to adopt a range of roles in order to gain access to environments and participants essential to my sampling strategy and thus fulfil my study aims. Hence I became aware that much of the role ambiguity and conflict was a product of strategies I adopted to gain and maintain research access, while at the same time avoiding the potential to become manipulative in so doing (Arber, 2006).

In the interviews with women or partners I was also aware of the need to manage similar role boundaries to those outlined in figure 3.1, but in a more predictable and structured manner than was possible during observation field work. This was, in part,
because I had anticipated the likely role demands I would encounter within the interview situation and had made decisions about how such boundaries would be best managed to maintain both participant and researcher safety in advance of the interview taking place. Strategies I adopted included restricting myself to providing brief general information about treatment side effects, when asked, and suggesting that the woman / partner contact a named treatment team member for further discussion should they have any specific treatment or illness-related concerns remaining at the end of the interview. If a specific request was made for psychosexual information or support this was addressed on completion of the interview once recording had stopped. The information given under such circumstances normally comprised general information about the types of psychosexual interventions for different types of female sexual difficulties together with information about how to access appropriate specialist services through their general practitioner or by direct access / self-referral. I also encouraged women to mention any persistent sexual difficulties or concerns to their treatment team at the next oncology follow-up clinic appointment so that a more accurate assessment of their post-treatment recovery could be made.

3.6 Research Procedure

This section provides detail of the research processes undertaken in order to gain and maintain access to the research sites for the purpose of participant observation in follow-up clinics together with the strategies used to identify and recruit interview participants. This section also provides a description of the clinical environments in which the oncology follow-up clinics were situated in order to appreciate the influence of clinical environments upon the patient experience of care and the constraints on health professionals present in those environments. This information is of particular relevance to findings presented in chapter six: The Culture of the Clinic.

3.6.1 Research Context and Sites

Some details of the research sites are not presented in this thesis in order to reduce the likelihood that the research settings and participants may become identifiable by future readers of this thesis. This study collected research data from two contrasting NHS Trust based cancer centres in London and the south of England. The rationale for inclusion of
two sites was to be able to explore the context specific contribution or influence of different clinical environments, staff group characteristics and service processes on women, partner and health professional's experience of sexual health assessment within pelvic radiotherapy follow-up. While the Trusts where the study took place are NHS facilities, they also provide specific resources for the management of private patients receiving cancer treatment. Both NHS and private patients took part in patient interviews for this study although participant observation of follow up clinics took place in NHS clinics only.

Strategy and policies that govern the overall provision of services for women with pelvic cancers have been standardised across England through the implementation of the NHS Cancer Plan (2000) and associated Improving Outcomes Guidance for Gynaecological, Urological and Colorectal Cancers (1999, 2002, 2004) through the NHS Executive and more recently the National Institute of Clinical Effectiveness [NICE]. Implementation of policy and guidance documents are audited regularly through a peer review quality assurance process that adheres to centrally agreed standards published in the “Manual for cancer services” (DH, 2004) and individual NHS Trust results are made available as a key quality feedback loop mechanism.

3.6.2 Preparing to Enter the Field
Preparing to conduct fieldwork in clinical environments and to interview patients has a substantial lead in period that takes place before, during and after the preparation of formal submissions for ethical and research and development (R&D) approval. Having identified key stakeholders at each Trust I spent time holding meetings with individuals who were crucial to gaining access to the clinical environment and to specific staff and patient groups. These were followed by individual and group meetings as necessary with nursing, therapy radiographer and psychological support staff responsible for providing a clinical service for women eligible to take part in the study (see Table 3.2).

Informing staff at all levels of the organisations who had agreed to support the study was important to ensure that should women seek further contact with their clinical team as a result of taking part in the study, then those staff would be aware of the research in progress and would be prepared for such an approach. In addition, a condition of ethical approval was that I could refer women with an identified and agreed need for ongoing information or support back to their treatment team for discussion and onward referral where necessary. Last, but by no means least I felt that these practitioners may be
interested to hear about a clinical study that explored an element of their current practice, the findings of which may have implications for role conduct, staff development and service delivery.

Table 3.2: Summary of Stakeholder Meetings

<table>
<thead>
<tr>
<th>Research Site A</th>
<th>Research Site B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chief Nurse / Director of Quality</td>
<td>Cancer Services Directorate Lead Nurse</td>
</tr>
<tr>
<td>Consultant Clinical Oncologists x 3</td>
<td>Consultant Clinical Oncologists x 3</td>
</tr>
<tr>
<td>Superintendent Radiographer</td>
<td>Radiotherapy Services Manager</td>
</tr>
<tr>
<td>Clinical Nurse Specialists x 3 for:</td>
<td>Clinical Nurse Specialists x 3 for:</td>
</tr>
<tr>
<td>Gynae-oncology</td>
<td>Gynae-oncology</td>
</tr>
<tr>
<td>Lower GI Cancer</td>
<td>Colorectal Cancer</td>
</tr>
<tr>
<td>Uro-oncology</td>
<td>Urology</td>
</tr>
<tr>
<td>Therapy radiographers x 2 group discussions</td>
<td>Research Radiographer</td>
</tr>
<tr>
<td>OPD Nurse Manager x 2</td>
<td>OPD Nurse Manager</td>
</tr>
<tr>
<td>OPD nurses x 1 group presentation</td>
<td>OPD nurses x 1 group presentation</td>
</tr>
<tr>
<td>Gynae-oncology ward sister</td>
<td>Network Research Manager</td>
</tr>
<tr>
<td>Radiotherapy Department Nurses x 2</td>
<td>Group Discussion with Psychological</td>
</tr>
<tr>
<td></td>
<td>Support Services Staff</td>
</tr>
</tbody>
</table>

Interestingly, while higher level stakeholders acted as official gatekeepers to the Trust environment, staff and patient groups, I noticed that it was individual outpatient department nurses and medical secretaries who were key to enabling (or delaying) access to the information and local processes that would be essential for effective participant observation in the clinics and the management of patient recruitment processes.

3.6.3 Entering the Field and Experiencing the Clinic

Research Site A was a large urban cancer centre in the south east of England housed on two separate clinical sites; radiotherapy services were provided at both Trust sites. All forms of cancer treatment and supportive care services were offered at this centre although some women received their surgical treatment at other Trusts and attended the cancer centre solely for radiotherapy or chemo-radiation treatment. Hence, medical follow up was either conducted at the cancer centre or was shared between the cancer centre and the referring consultant at another NHS Trust usually within the cancer network in which the cancer centre was located.
The outpatient department (OPD) at site A1 was a compact department with windows at one end of the waiting area that let in natural light. The décor was modern neutral shades with up-lighting, creating a calm and open airy space for patients to wait in. There was a sandwich and refreshments snack bar adjacent to the seating areas. The chairs were comfortable purple fabric and beech wood frame chairs, less obviously “NHS Issue” than the ones at the other Trust site (A2). They were arranged in rectangular groupings, facing inwards with a small rectangular table in the centre of each grouping with magazines for patients to read.

The reception desk for the department was at the entrance to the seating area and patients booked in at the desk prior to taking a seat in the waiting area. An electronic display informed patients which clinics were in progress and their location within the department. In the waiting area there were a mixture of wall hangings including framed art prints and notice boards. One notice board contained a range of cancer related information; some were Trust produced e.g. a skin camouflage service, while others were from national patient support groups such as a group for rare cancers. Another notice board had a series of bar charts displayed that related to this NHS Trust’s target performance regarding outpatient waiting times, number of cancelled operations, complaints and outcomes / actions taken, letters of praise and a copy of the Patient’s Charter.

Adjacent to the corridor and entry to two of the suites of consulting rooms was a rack of patient information leaflets on a variety of topics related to specific types of cancer and their investigation and treatment. These leaflets were from the Trust’s own patient education / information service. Within the OPD there was a phlebotomy service and the department sister’s office was close to the main waiting area.

There were four main clinic consulting suites, each with a large self-contained office for the doctors to read medical notes, consult computer records, dictate annotations for patient notes and discuss relevant aspects with medical and nursing colleagues prior to entering the relevant consulting room to see the patient. Up to four individual consulting rooms could run simultaneously, dependent on the number of doctors available to see patients. There were usually two or three doctors and one clinic nurse in clinic unless visiting medical or nursing personnel were present. When the patient’s appointment time arrived the nurse working in that clinic called the patient’s full name and the patient accompanied her to sit in a consulting room to wait for the doctor.
The main outpatient waiting area at site A2 was a larger open plan space with windows on two sides that let in natural light and floral curtains to soften the frames. There were a few potted green plants placed around the room and, as at the other Trust site, the walls were decorated with a mixture of notice boards, posters and framed art prints.

The seats were comfortable high backed chairs covered by a "cheerful" red fabric and beech wood finish. Although clearly "NHS Issue" they were clean, smart and arranged to make the most of the space available. Some were placed around the perimeter of the room, reminiscent of the geriatric ward day rooms of my student nurse days in the 1970s. Others were set in clusters of eight (rows of four facing each other) with low wooden tables to place magazines on for patients to read while waiting. There was a TV in the corner, near to the entrance / exit to the waiting room, but with the volume turned down so no-one could hear it and no-one seemed to be watching it.

The reception desk was furthest away from the entrance to the waiting area. Several reception staff and some clinic nurses were sitting behind the desk or using computers and collecting patient files from this area. An electronic display informed patients which clinics were in progress and their location within the department. An announcement was made if there was a particularly long wait associated with any given clinic.

On arrival in OPD patients booked themselves in at the reception desk and took a seat to wait until they were called through to the clinic areas by a nurse. The waiting area and clinic consulting rooms were separated by a corridor and swing doors.

At regular intervals a clinic nurse appeared at the door and shouted out patients' names in batches of two to four. The patients then followed the nurse through to individual clinic waiting areas adjacent to the consulting rooms where they would be seen by the doctor.

The role of the clinic nurse at both sites appeared to comprise retrieving patient results from the computer system or Trust departments, ensuring the smooth flow of patients and doctors in and out of the consulting rooms and directing patients to other hospital departments or to reception to arrange future diagnostic tests or follow-up appointments. Nurses also acted as chaperones for intimate examinations (vaginal or rectal examinations by male medical staff on female patients) and ensuring the necessary equipment for such examinations was available and replaced when used. If the patient appeared frail, nurses provided assistance to patients required to (un) dress for examinations and assisted their mobility in the clinic environment. Routinely, the clinic nurse remained outside the consulting room, although occasionally research nurses or clinical nurse specialists would come to the clinic to participate in consultations where they had identified a need to make
contact with specific patients, normally those on clinical trials where toxicity data were being collected or where there was a specific clinical need. There were separate private patient OPD waiting and consulting suites at each site of the Trust and these operated independently from the NHS OPDs.

Research Site B
Site B was a small cancer centre on one site within the grounds of a general NHS Trust serving a town in the south east of England and a number of predominantly rural local village communities. All acute cancer services were provided from this site, although it was common for patients to receive their medical follow up at cancer units in other Trusts located within the same cancer network.

At site B there was no natural light in the waiting area of the oncology outpatients department, being in the centre of the two-storey building, but the décor was bright (cream) and the walls decorated with art prints. The seats (green / pink fabric with beech wood frames) were arranged in clusters of six, two rows of three facing each other with a low wooden table in the centre and a selection of magazines for patients to read. There were no patient information / education materials adjacent to the consulting rooms but a small selection of locally produced materials about the cancer centre were located in the main reception, adjacent to a coffee shop run by the local WRVS. There was a notice board which had details of BACUP, lymphoedema services, Macmillan Cancer Relief and some local cancer self help groups. There were also a range of services advertised related to promoting general well-being such as relaxation / visualisation, CRUSE, "Look Good Feel Better", a cancer dietician clinic and wig provision.

The patients arrived at a main reception desk (for the cancer centre outpatient and day care departments) and were then directed by reception staff to a waiting area next to the clinic rooms. This was a quieter area in which to sit, without much "passing traffic" of the human or non-human variety. Waiting patients were seated in a long strip of chairs placed down the middle of the department, with consulting rooms arranged all around the periphery, some of which were in close proximity to the seating area, while others were a little further away. The reason for mentioning this proximity was that the rooms adjacent to me were within ear shot as I sat there. I became aware that without too much difficulty I could hear virtually every word the doctor and a patient were exchanging, even though the room door was closed. It made me wonder that when clinics were held in these rooms,
should there be a need to discuss sensitive issues, would patients be reluctant to do so, given the possibility of being overheard?

Each consulting suite consisted of two or three consulting rooms and a small office for the doctors and nurses to consult medical records, access patient results by phone or via the computer system and dictate patient record annotations after each consultation. The space available for staff to work appeared cramped and usually meant only one of the three doctors in clinic, usually the consultant, could be seated at any one time. Again it was possible to hear what was being said on either side of the connecting doors to the patient consulting rooms. The name of the consultant, attending doctors and clinic nurse were displayed immediately outside the clinic door. Doctors were referred to by their full title: Dr. A. Bloggs and the nurse by their first name only.

There appeared to be one staff nurse attached to each clinic, adopting a role that was indistinguishable from that witnessed at the other Trust study sites (A1&2). Again the nurses did not routinely stay with patients during consultations; instead they were busy fetching equipment or notes for the doctors and calling patients when it was their turn to be seen.

3.6.4 Field Notes

Shortly after leaving the clinic setting I compiled field notes that captured the process and content of each observation period, both those formally sought through the observation framework and schedule together with interactions that were incidental yet influential on my developing awareness of the culture of the clinic (see chapter six). These field notes described what I had encountered during that period of participant observation and included reflexive insights into my actions, reactions and emotional response to what I had observed and my evolving role as a participant observer.

I also made brief field notes in relation to my experience of the research interviews with participants. I did not record a field note in relation to every interview but instead noted memorable occurrences, comments or behaviours emanating from the participant or interview context, together with my emotional, cognitive and behavioural responses. This data formed important elements of my reflexivity (see section 3.8.1) and assisted me in data interpretation during analysis of the interview transcripts.

Hammersley and Atkinson (1995) differentiate between types of field notes, categorising them into what they referred to as observer description, analytic notes and
memos and fieldwork journals. Field notes that comprise observer descriptions are perhaps self-explanatory, being a detailed, albeit always incomplete, written record of what the participant observer saw, heard and did in the field during that particular period of observation. As discussed previously, my descriptive field notes comprised an observation schedule that captured the specific topics discussed during follow up consultations, the actors present in that setting and their contribution to that interaction. This was combined with a written summary of the observation process in terms of the context, actions and impressions observed, together with my thoughts and responses to what I had experienced.

Some of my observation field notes were largely descriptive accounts of the follow-up consultations witnessed, but these were usually combined with speculative comments that could be revisited during the process of analysis and be used to sensitise the researcher's focus during the interview phase of data collection which was to follow.

Analytic notes made at this point often fell short of integrating theoretical ideas and interpretations with observed practice but were normally a means to remain actively aware of and engaged in this reflexive process of enquiry. Further analytic notes and memos were constructed in response to and as an integral part of the data analysis process, assisted by the software design capabilities of NVivo (version 2.0) used for this purpose. Where analytic notes were related to ideas about specific research developments, an adaptation to procedure or reinterpretation of theoretical principles, a separate field note was made more akin to the nature of those found in a field note journal (Hammersley & Atkinson, 1995).

3.6.5 Sampling Strategy: Theory and Reality

In qualitative research the approach taken to sample data, assuming the capture of a “total population” is not usually possible, departs from the representational logic of positivism and the natural sciences (Mason, 2002). In contrast, sampling in a focused ethnography is guided by the strategic relationship between the data that is possible to collect and the complexity of the socio-cultural phenomenon you are trying to explore. Here the ethnographer endeavours to identify an appropriate “…range of contexts or phenomena which will enable [them] to make strategic and possibly cross-contextual comparisons, and hence build a well-founded argument.” (Mason, 2002, p.124). There is a “strategic purpose” to determining the range of data to sample, based on the nature and scope of the
study's research questions. The range of data sought is commonly determined by a synthesis of the researcher's theoretical and empirical logic (Mason, 2002). In both positivist and interpretivist research, use of the term sampling is often taken to refer solely to the process by which one identifies how many of which key informants should be included in the study of any given phenomenon in order to answer one's research question(s). However within ethnography, sampling refers to decisions an ethnographer makes about the where, when, what and who of participant observation, interviews and documentary sources in their data collection strategy. Hammersley and Atkinson (1995) address the concept of sampling at both a “case selection” or macro level and “within case” sampling or micro level. The macro level is thus defined by decisions a researcher makes in relation to the selection of a phenomenon they wish to explore, whereas sampling at a micro level relates more to decisions regarding the dimensions of the phenomenon considered essential to capture through any given research methodology and associated data collection methods. At this micro level, Hammersley and Atkinson (1995) consider there to be three main dimensions around which ethnographers sample data and these are time, people and context.

Thus the scope and volume of data a qualitative researcher pursues is determined by a strategy often referred to as theoretical or purposive sampling. Theoretical sampling originates from the work of Glaser and Strauss (1967) in their development of grounded theory as a research approach. Theoretical sampling involves the iterative process of constant comparative analysis whereby the researcher systematically “...collects, codes and analyses data and decides what data to collect next in order to develop a theory as it emerges [from the research data].” (Morse & Field, 1996, p.130). In theoretical sampling the process of data collection ceases when data saturation is reached, that is when no new categories or new characteristics defining existing categories are emergent from the data. However, many qualitative researchers adopt the principles of theoretical or purposive sampling without adhering to the precise procedure as described by Glaser and Strauss (1967).

This study adheres to the principles of purposive sampling in selecting particular categories of participants (patients, partners, clinical oncologists, nurses and therapy radiographers), types of clinical setting (gynaecological and colorectal follow-up clinics) and geographical locations (urban and rural cancer centres) which are meaningful to the exploration of the phenomenon and research questions at the core of this study. In
purposive sampling there is an interactive shaping of data generation processes based on perceptions arising from reflexive insights and interim analysis of the data as they evolve and their perceived relevance to the underlying aims of the study (Mason, 2002). In this study I experienced a tension between the expectations of a medical research community and ethical approval documentation that require a pre-determined sampling strategy based on the assumptions of its dominant (positivist) research paradigm and my desire as a novice ethnographer to adhere to a contrasting sampling logic. However, as will be discussed later in this chapter, it is not uncommon to experience tension between research theory and the pragmatic realities of research procedure when access to participants is both voluntary and influenced by a range of factors beyond the control of the researcher.

3.6.6 Participant Observation: Sampling Dimensions of Context and Time

The rationale for using participant observation in addition to in-depth interviews was to capture the reality of medical follow-up practice within its naturalistic setting. I felt that observing consultations which incorporated radiotherapy toxicity / morbidity assessment would elicit the frequency and nature of discussions in relation to the sexual consequences of pelvic radiotherapy as experienced by key actors (patients, partners and health professionals) within the clinic setting.

Participant observation also provides insights into individual and organisational cultures of both patient assessment and the provision of psychosexual care as an element of psychosocial practice within the context of contemporary cancer service development and delivery associated with the NHS Cancer Plan (DH, 2000) and subsequent Supportive and Palliative Care Policy Guidance (NICE, 2004a).

In order to explore the diversity of individual medical staff’s consultation practices and to explore the contribution of setting and resource on both the patient and professional experience of follow up I decided to observe routine consultant clinical oncologist NHS follow up clinics held at both cancer centres (research sites A & B). These clinics included women attending for follow-up at different time periods post-treatment (six weeks to four years) together with women at earlier points in their treatment journey such as those who were newly diagnosed or currently receiving cancer treatment (on-treatment review). The diversity of women attending the clinics offered the potential to elicit changing assessment, information and support priorities for both patients and health care professionals across different personal circumstances and time points in clinical oncology practice.
Although my initial intention was to observe clinics reviewing women with gynaecological (cervical and endometrial), colorectal (rectal and anal) and urological (bladder) malignancies it soon became evident that there were very few women with bladder cancer attending the urology clinics at either research site. Through scrutiny of patient lists of women who had completed pelvic radiotherapy over the relevant time period (between three months and two years prior to study commencement) only 21 women had been identified with a diagnosis of bladder cancer. In addition, scrutiny of their electronic patient records revealed that those women attending for follow-up were more likely to be frail, have a number of co-morbid conditions, aged over 75 and not in a current relationship. I therefore considered it unlikely that I would encounter many consultations with this sub-group of women (with bladder cancer) where sexual issues were likely to be a clinical priority and decided to focus on attending the gynaecological and colorectal consultant clinics at both research sites. I started observation at research site A in September 2005 and at research site B in October 2005.

Figure 3.2: Observation Framework Domains

I attended all NHS clinics where follow-up of my target population of women was to take place and this totalled five consultant clinics (three colorectal, two gynaecological) at
site A, one nurse-led on treatment review clinic at site A and four consultant clinics (two colorectal, two gynaecological) at research site B.

The actual process of observation and associated field notes were focused around the domains of an observation framework devised by Spradley (1980). This observation framework (see Figure 3.2) helped me to structure my observation so that I included the key elements of the context (social situation: clinic environment), participants (actors: doctors, nurses, patients and partners) and the processes (activities) of medical follow-up at these hospitals. The content of key clinical documents such as pelvic radiotherapy consent forms and patient information materials were also sampled as part of the clinic context.

In this way I was capable of observing the components of a continuously evolving social situation; the routine practices of the clinical oncology follow-up clinic. As I became engaged in participant observation within the clinic setting I experienced first hand the rapidity and complexity of medical consultations. I also witnessed the many ways in which the doctor-patient encounter could be fragmented when other health professionals and care systems interacted with medical staff in the clinic. There were multiple interruptions both during and between patient consultations that required clinicians to respond to a range of demands on their time and clinical focus. Such interruptions were more prevalent at study site B than at site A and included phone calls from in-patient units regarding patient management issues, requests by nurses to write or amend chemotherapy prescriptions, requests by radiographers to authorise treatment planning instructions, enquiries from medical, nursing or radiography colleagues, searching for patient results (phone or via computer systems) and liaison with other hospital departments.

At the stage of study design and ethical approval I expanded each of Spradley’s (1980) observation domains by identifying the specific questions I needed to consider in order to focus my observation in the clinical setting (Appendix 6). However, in what was at times an apparently “chaotic” clinical environment, as has been found in other studies conducted in out-patient settings (Allan, 2007), this observation strategy proved difficult to use in the field. I therefore had to devise a concise observation schedule to record not only which topics were prevalent within the consultation but also which of the actors (see Spradley, 1980, figure 3.2) in the consultation raised the topic, thus shaping the consultation agenda (Appendix 7).
3.6.7 Interviews: Sampling the People Dimension

The original sampling strategy for the in-depth interview component of data collection proposed recruitment from both cancer centres to maximum participant numbers of:

- 40 women who had completed radiotherapy for the management of pelvic malignancy
- 10 partners of women interviewed for the study.
- 10 health care professionals directly involved in the care of women who have had pelvic radiotherapy

This sampling strategy was devised in order to explore views about the assessment of sexual consequences of pelvic radiotherapy by those deemed to hold both personal and professional experience of this treatment late effect. Figure 3.3 provides a summary diagram of the original sampling strategy for this study.

**Figure 3.3: Summary of Initial Sampling Strategy**

Purposive sampling sought to identify women that could offer the diversity of patient experiences within the anticipated participant population. The sample was to incorporate
two groups of women (n =10 per group, per research site) thus ensuring that those with gynaecological (cervical and endometrial cancer) and non-gynaecological (bladder and ano-rectal cancer) diagnoses were included in the study. Women who had completed pelvic radiotherapy for non-gynaecological malignancy were considered important to include as they experience vaginal toxicity associated with pelvic irradiation yet relatively little has been published to date about women’s sexual recovery after completing radiotherapy for bladder, anal or rectal cancer therapy.

Further scrutiny of the sample ensured inclusion of women at four key time points post pelvic radiotherapy. These time points captured the different patient and health professional priorities, patient experiences and sexual recovery/rehabilitation processes thought to be manifest in the patient population. Women at three, six, 12 and 24 months post-pelvic radiotherapy treatment completion were invited to participate. The time points coincided with patient’s routine medical follow-up schedule, hence it was not anticipated that women would have to attend additional clinic appointments in order to take part in the study, thus minimising participant and research site inconvenience and resource cost. These time points were also selected to allow treatment late effects associated with pelvic radiotherapy to become apparent and to permit tentative comparisons between patient groups to be made with regard to their experience of resumption of sexual activity within the context of their overall recovery and adjustment post-treatment.

Due to the sensitivity of the topic of this study, strict inclusion and exclusion criteria were devised (see Table 3.3 for a summary of participant inclusion/exclusion criteria) in order to protect the most vulnerable women in this patient population, whilst including women to whom this topic may be of interest. Following scrutiny of patient's medical records, women who had completed radical radiotherapy treatment (with or without concurrent chemotherapy) for cervical, endometrial, bladder, anal or rectal malignancy at either of the study sites, and who met the study inclusion criteria, were sent a written invitation to take part in the study. Patients were recruited through routine follow-up systems via their consultant clinics. Suitable patients were initially identified via clinic lists and through review of the patient’s medical notes in consultation with an appropriate member of their treatment team. A total cohort of 238 women (153 women with a gynaecological cancer diagnosis, 85 women with a non-gynaecological cancer diagnosis) met the diagnosis, treatment and time period post-treatment inclusion criteria from an initial review of electronic patient records.
Table 3.3: Summary of Participant Inclusion / Exclusion Criteria

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women with a primary diagnosis of cervical, endometrial, bladder, or ano-rectal cancer</td>
<td>Women receiving external beam radiotherapy for vulval, ovarian, lymphoma or haematological malignancy (Total Body Irradiation – TBI)</td>
</tr>
<tr>
<td>Women who completed radical external beam pelvic radiotherapy (+ / - concurrent chemotherapy, + / - maximum of HDR brachytherapy treatments) 3, 6, 12 or 24 months previously</td>
<td>Women receiving brachytherapy alone for treatment of pelvic malignancy</td>
</tr>
<tr>
<td>Women who have engaged in some form of sexual expression within 12 months of treatment commencement</td>
<td>Women receiving pelvic radiotherapy with palliative intent</td>
</tr>
<tr>
<td>Partners of women participating in the study in light of knowledge of both their partner’s diagnosis &amp; informed consent</td>
<td>Prognosis of &lt; 6 months or any evidence of progressive disease</td>
</tr>
<tr>
<td>Health professionals with current experience of post-treatment follow-up for women receiving external beam radiotherapy for cervical, endometrial, bladder, anal or rectal cancer who give informed consent</td>
<td>Women currently receiving active treatment for cancer</td>
</tr>
<tr>
<td></td>
<td>Women who have never been sexually active or have not engaged in any form of sexual expression for greater than 12 months prior to treatment commencement</td>
</tr>
<tr>
<td></td>
<td>Women or partners with restricted verbal expression of English</td>
</tr>
<tr>
<td></td>
<td>Women, partners or health care professionals who have not given informed consent to participate</td>
</tr>
</tbody>
</table>

Further scrutiny of the electronic patient records identified those women where one or more of the exclusion criteria applied, leading to exclusion of 162 women.

Table 3.4: Summary of Patient Participant Exclusions by Primary Diagnosis

<table>
<thead>
<tr>
<th>Primary Diagnosis of Patient Exclusions</th>
<th>No. of exclusions / Total Sample (% of total sample)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Endometrium</td>
<td>50 / 82 (60.9%)</td>
</tr>
<tr>
<td>Cervix</td>
<td>44 / 71 (61.9%)</td>
</tr>
<tr>
<td>Bladder</td>
<td>19 / 21 (90.4%)</td>
</tr>
<tr>
<td>Rectum</td>
<td>39 / 45 (86.6%)</td>
</tr>
<tr>
<td>Anus</td>
<td>10 / 19 (52.6%)</td>
</tr>
</tbody>
</table>
Table 3.4 provides a summary of the proportion of women with each primary diagnosis who were considered unsuitable to be approached to participate in this study and table 3.5 offers a summary of the reasons for exclusion of these women from this research.

**Table 3.5: Reasons for Patient Exclusion from Study**

<table>
<thead>
<tr>
<th>Reason for Patient Exclusion</th>
<th>No. of Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Progressive / Advanced or Active Disease</td>
<td>56</td>
</tr>
<tr>
<td>Single / widowed &amp; living in sheltered accommodation or with adult child, aged 80 years (mean)</td>
<td>46</td>
</tr>
<tr>
<td>Co-morbidities likely to affect sexual well-being*</td>
<td>27</td>
</tr>
<tr>
<td>Non-resident in UK</td>
<td>20</td>
</tr>
<tr>
<td>Receiving Palliative Treatment</td>
<td>15</td>
</tr>
<tr>
<td>Active Clinical Problem</td>
<td>12</td>
</tr>
<tr>
<td>Mental Health Concerns**</td>
<td>8</td>
</tr>
<tr>
<td>Lost to Follow-up</td>
<td>8</td>
</tr>
<tr>
<td>Interpreter Needed</td>
<td>7</td>
</tr>
<tr>
<td>Patient Deceased</td>
<td>5</td>
</tr>
<tr>
<td>Receiving Active Treatment</td>
<td>3</td>
</tr>
<tr>
<td>Acting as carer for Husband</td>
<td>3</td>
</tr>
<tr>
<td>Declined Feminine Care</td>
<td>2</td>
</tr>
</tbody>
</table>

* Pelvic exenteration, concurrent diagnosis of breast cancer, receiving anti-oestrogen medication
** Concurrent mental health diagnosis of depression, anxiety, psychosis, cognitive impairment, dementia

A letter of invitation to participate in the study from the patient's consultant clinical oncologist (Appendix 8) was sent by post a minimum of seven working days prior to their next follow-up appointment. The study invitation letter was accompanied by a patient information sheet (Appendix 9) that outlined the study aims / purpose and provided details of what participation in the study would entail for an individual woman. Participants were invited to contact the researcher to discuss any aspect of the study prior to reaching any decision whether or not to take part. The invitation letter included a reply slip where the woman could indicate her willingness to participate or otherwise. Confirmation or refusal to participate was communicated to the researcher via post, telephone or email in advance of routine clinic attendance.

The woman's GP was informed by letter (Appendix 10) of their participation in the study, accompanied by an information leaflet about the study and researcher contact details. The rationale for informing the patient's GP related to ethical dimensions of the

**NB Nos. total greater than 162 as women often had more than one reason for study exclusion**
study whereby the GP would be aware of her participation in this research should she subsequently wish to speak to her doctor about issues that had arisen as a result of taking part in the research interview. Women who agreed to take part in the interview element of the study were asked to provide written consent to participate at the time of the interview (Appendix 11) after clarification had been sought that they had read the patient information sheet sent to them by post and had no unanswered questions remaining about their participation. Women were also asked to indicate on the consent form what they wished to happen to their interview recording and transcript and whether or not they were prepared to give consent for the researcher to send a study invitation letter to their partner.

Partners were invited to participate in order to gain insights about the impact of the experience of illness / treatment on the couple relationship and more specifically on the sexual / intimacy elements of that relationship. A sample of partners of women who participated in the study (maximum 10 partners) was approached to take part. Partners were identified as belonging to two distinct groups, one where the patient had experienced minimal / no sexual difficulties post- illness / treatment (n = 5) and the second group where the patient had reported significant sexual difficulties associated with her illness / treatment (n = 5). Partners were approached by letter following written agreement from the woman concerned and given a minimum of five working days to consider study participation following receipt of written information (Appendix 12) about the study.

Selected health care professionals (clinical oncologists, clinic or departmental RT nurses, clinical nurse specialists (CNS) in gynae-oncology, uro-oncology or colorectal cancer and therapy radiographers) working in the care of women receiving pelvic radiotherapy were invited for interview to establish their views on the assessment of radiotherapy toxicity / late effects, psychosexual impact, information and support offered to this client group, together with their estimation of available resources and satisfaction with current service provision regarding this aspect of psychosocial practice within clinical oncology. The health professional sample was sought from each research site (maximum of 10 health care professionals per site) and purposive sampling endeavoured to include members of each of the relevant disciplinary groups involved in these women's treatment, care and support.

Health professionals were invited to give written informed consent for both interview and observation following verbal discussion and written information (Appendix 13) about the study. A minimum of 48 hours was given for colleagues to consider their decision to participate in the study. Researcher contact details were made available to all
potential study participants for the purpose of discussion or clarification of the study and its purpose.

3.6.7.1 Demographic Details of Study Participants

Demographic data relevant to the study focus were retrieved from individual patient's medical records and interview participants and included details as outlined in Tables 3.6 and 3.7.

Table 3.6: Demographic Details for Patient Participants

<table>
<thead>
<tr>
<th>Disease / Treatment Characteristics</th>
<th>Patient Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Diagnosis</td>
<td>Age at time of study</td>
</tr>
<tr>
<td>Clinical Stage</td>
<td>Ethnicity &amp; Religion</td>
</tr>
<tr>
<td>Adjuvant/ Concurrent Treatment</td>
<td>Relationship Status</td>
</tr>
<tr>
<td>Time post-treatment Completion (months)</td>
<td>Menopausal Status &amp; HRT provision</td>
</tr>
<tr>
<td>Treatment Fields &amp; Phases</td>
<td>Smoking Status</td>
</tr>
<tr>
<td>Total Dose, Fractionation</td>
<td></td>
</tr>
<tr>
<td>Radiation Technique (External Beam, Conformal RT, Intensity Modulated RT, High Dose Rate Brachytherapy)</td>
<td>Relevant co-morbidities: anxiety, depression, diabetes, dermatological or collagen disorders, vascular disorders</td>
</tr>
<tr>
<td>Record of vaginal stenosis in medical notes</td>
<td>Pre-existing sexual difficulties</td>
</tr>
<tr>
<td>Record of provision of vaginal dilators to woman or discussion of same</td>
<td>Relevant partner characteristics</td>
</tr>
<tr>
<td>Record of any sexual concerns in medical notes</td>
<td></td>
</tr>
</tbody>
</table>

Table 3.7: Demographic Details for Partner & Health Professional Participants

<table>
<thead>
<tr>
<th>Partner Characteristics</th>
<th>Health Professional Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at time of study</td>
<td>Age at time of study</td>
</tr>
<tr>
<td>Gender</td>
<td>Gender</td>
</tr>
<tr>
<td>Ethnicity &amp; Religion</td>
<td>Ethnicity &amp; Religion</td>
</tr>
<tr>
<td>Relevant medical history in relation to study focus</td>
<td>Years post-qualification</td>
</tr>
<tr>
<td>Relevant co-existent sexual concerns / difficulties</td>
<td>Years in oncology / clinical oncology</td>
</tr>
<tr>
<td></td>
<td>Primary Discipline / Grade</td>
</tr>
<tr>
<td></td>
<td>Presence of any relevant post-qualification specialist training (women’s health / sexual health / sexual counselling / psychological / mental health training)</td>
</tr>
</tbody>
</table>
Demographic details (Appendix 14) of women who refused to participate or who did not reply to the study invitation were also recorded in order to analyse the presence of sampling bias inherent to the study design and voluntary nature of patient participation.

3.6.8 Reflections on an evolving sampling strategy

The original intention of the purposive sampling strategy was to access key informants and clinical settings from each of the research sites in order to generate data that would be capable of adequately exploring this study's central research aims.

In relation to participant observation data, access to clinical oncology follow up clinics at both research sites was unproblematic. I commenced data collection at research site A, progressing to Research site B one month later. In adopting the principles of purposive sampling I stopped data collection at site B when the follow up consultations did not appear to reveal any new content or process elements and were largely repeating previous observations. At this juncture it is perhaps appropriate to say that the precise characteristics of each consultation were of course unique given the nature of individual participants, context and time factors operating on that occasion. Nevertheless, for the purposes of sampling in relation to the phenomenon under study, no new data categories were emergent.

The collection of interview data from key informants across both research sites was however more challenging than anticipated for a number of reasons which will now be explored. Despite being given Trust R&D approval and departmental support to proceed with patient recruitment, difficulties in achieving access to relevant patient treatment lists at research site B were repeatedly encountered. The limited time frame available for data collection meant that after several unsuccessful approaches to overcome the block to patient recruitment, a decision had to be reached to abandon patient data collection at that site as long as research integrity and rigor could be maintained. After discussion with my supervisory team it became clear that the quality and quantity of patient data necessary for the study could be achieved from research site A alone where patient access had been readily established.

The characteristics of the patient populations at research sites A and B were deemed to be comparable in terms of clinical diagnosis and stage, treatment plans, age, ethnicity and social class. Treatment approaches across cancer centres had been standardised through the implementation of relevant Department of Health Cancer Policies and Improving
Outcomes Guidance (NICE). It could be argued, therefore, that satisfactory capture of patient perspectives could be achieved through a single research site if necessary. Participant observation and individual interviews with health professionals were conducted at both research sites and this enabled me to confirm the comparability of both the patient characteristics and treatment strategies offered at each research site. Data emanating from the participant observation and health professional interviews appeared to adequately capture the organisational and service delivery factors that were context dependent and that may have been influential in shaping the experience of individual women with regards the assessment and management of their sexual recovery post-treatment.

The study patient invitation letters were sent out in five "waves" in an endeavour to recruit from a diverse patient sample representing women with different cancer sites (gynaecological versus non-gynaecological) and time post treatment (three, six 12 and 24 months). However, while the recruitment of patients attempted to pursue a broad range of patients, there was no control over the categories of patients who ultimately responded to the study invitation letters. Hence subsequent "waves" of patient invitation letters were sent to women who appeared to have the greatest potential to contribute to the diverse characteristics of the desired research sample should they agree to participate. All women who volunteered to participate in the study and met the entry criteria for participants were recruited. Response rates and sample details presented in chapter four illustrate the need to make pragmatic sampling decisions to include all eligible women who agreed to take part in the study as opposed to rigidly adhering to initial sampling strategy.

Furthermore, recruitment of individual patient's partners also proved to be determined by the presence of a current partner, the willingness of women to permit me to approach their partner to take part and finally the partner's willingness to respond to this invitation given the sensitive nature of the research topic. It was not possible to recruit partners to achieve an equal distribution of those where sexual difficulties were present versus those where sexual recovery post-treatment had been satisfactory, although analysis of partner data took account of this in the interpretation of study findings. A summary of the actual sample of participants who contributed to this study can be found in chapter four.

3.6.9 Interview Development and Context
Concepts from a theoretical framework for psychosexual assessment devised by Hawton (1985) as outlined in Figure 3.4, together with selected literature review findings and
clinical experience in both cancer care and psychosexual therapy were used to develop
the content of three separate interview schedules (Appendices 15-17) for study
participants. Hawton’s (1985) psychosexual assessment model is based around three
inter-related domains that influence the development and manifestation of an individual’s
sexual script (Andersen et al. 1997) based upon their underpinning beliefs and values.

Figure 3.4: Assessment Model for Development of Sexual Difficulties

The patient and partner interview questions contained items that explored the physical,
psychological or emotional and interpersonal or relationship elements that are thought to
contribute to the individual and couple’s experience of their sexual relationship.
Furthermore, demographic details obtained from both medical records and from patient
and partner participants also captured different elements of these domains.
The temporal aspects of Hawton’s (1985) model were also relevant to the interview
process, exploring the view’s held by both the woman and her partner with regards to what
factors, if any, impacted on their sexual relationship before the cancer diagnosis, were
precipitated by their illness and its treatment and finally those factors post-treatment that
the couple felt maintained their sexual relationship in its present state.
The setting for patient, partner and health professional interviews was most often a vacant
consulting room within the outpatient department of the Trusts involved in the study. Some
of the women and partners requested to be interviewed in their own home or at their place
of work in order to minimise disruption to their family or work lives, while some of the health professionals in the study preferred their private office space as an alternative venue. The key issue from my perspective was to be able to establish a private space that could preserve confidentiality and promote comfort in discussing sensitive or intimate elements of participant's illness and treatment experience. Initially I considered that more than one interview may be necessary in order to enhance rapport with participants and thus increase the likelihood of disclosure of sexual concerns. However, my experience during the interviews suggested that this was not necessary and so only one interview was conducted with each participant.

3.7 Data Analysis

Most commonly ethnographers work with unstructured data, in that there is no inherent or implicit set of categories applied by the researcher (Hammersley & Atkinson, 1995). However, in focused ethnographies such as this study one can find what could be referred to as semi-structured data through researcher creation of both observation and interview schedules to direct and manage both data generation and recording processes. It is therefore inevitable that the data emerging from both elements of this study contained some pre-determined data themes or categories that influenced the subsequent analysis.

3.7.1 Participant Observation Analysis using SPSS (version 14.0)

During initial periods of observation I endeavoured to make brief notes that I would then expand upon at the conclusion of each follow-up clinic. However, this approach soon proved inadequate in capturing the volume and diversity of verbal and non-verbal behaviours observed within individual consultations. I therefore undertook an interim analysis of my observation field notes to ascertain the most frequently occurring discussion topics. From this interim analysis I developed a structured observation schedule (Appendix 7) to enable more complete and rapid recording of both the discussion topics and identifying the “actor” who raised that topic within the consultation. I also recorded field notes on conclusion of each clinic observation period to record contextual information that may have had some bearing on the content and conduct of the follow-up consultations or clinic overall.
Although the data from this study could be said to be predominantly qualitative in nature, data elements emanating from participant observation were more meaningfully analysed and summarised through the appropriate use of descriptive statistics and non-parametric tests. Hence data from the observation schedules (see Appendix 7) were analysed using data analysis software Statistical Products and Service Solutions (SPSS version 14). Using SPSS created an opportunity to explore not only the frequency of topics discussed but data regarding the range of topics and relationships between different topics and participants.

Pearson's Chi-Square test was used to see whether or not there was a relationship between two sets of categorical data. SPSS generated a series of contingency tables in order to explore these relationships. The contingency tables generated, together with the $\chi^2$ statistic, Fisher's Exact Test, the degrees of freedom (df) and the significance value are reported for each variable comparison conducted (Field, 2005).

### 3.7.2 Interview Transcript Analysis using NVIVO (version 2.0)

Interview transcripts were analysed using a thematic analysis strategy as outlined by Hammersley and Atkinson (1995). These authors describe the simultaneous development of and assignment of data extracts to a conceptual or thematic framework generated by the researcher through progressive immersion in the data. Hammersley and Atkinson (1995) outline a generic approach to ethnographic data analysis which was adopted for this study comprising:

- Data Immersion
- Data Comparison: between data sources and in light of existing literature
- Concept Generation
- Identifying Conceptual or Thematic Patterns and Links in the data
- Coding Data in light of interim Conceptual or Thematic framework
- Interpretation of data in light of social context, time sequence and social actors (participants)
- Iterative re-coding and triangulation with further amendments to thematic framework
- Development of a Typology or Conceptual Model to summarise data categories

The interviews were recorded using a digital recorder and verbatim transcripts generated for the purposes of textual coding and subsequent analysis. Of the 49 interviews
conducted I personally transcribed five interviews and for reasons of time constraints and
the need to manage a relatively large data set I engaged a psychology clinical research
assistant to transcribe the remainder of the interviews. This enabled me to focus on
listening to the interview recordings and to check each transcript for accuracy. I listened to
and read each interview at least three times; correcting errors, filling in omissions where
audibility had been difficult and noting any completely inaudible passages. I also made
notes of the data categories that appeared to be present on each occasion and considered
any particularly important contextual information from my field notes. The interview
transcript was then imported to qualitative data management software, QSR NVivo
(version 2.0). This software enabled me to store, manage and retrieve elements of a
relatively large and complex data set through creating data sub-sets (patient participants,
partner participants and health professional participants).

The imported interview transcripts were coded in small sections using free nodes created
in the NVivo software that represented key concepts or sub-categories emerging from the
data. When sufficient coding had taken place and it was possible to identify links in the
data then grouping the concepts or sub-categories into over-arching categories, or
creating what is referred to as “tree nodes” within NVivo, took place. Initial data sub-
categories and categories were repeatedly compared and refined in an iterative process
that led to generation of the final categories and sub-categories presented in this thesis.

Visual representations of the categories and sub-categories were also created
through the modelling facility offered by NVivo (see appendix 18) as this visual
representation appeared to make it easier to explore data links than being immersed in the
coded data sections themselves. NVivo also facilitated the retrieval of all data extracts
coded under a particular category or sub-category which proved invaluable both during the
process of data analysis and comparison and in the identification of appropriate data
extracts to represent both the relevant category and data corroboration between different
participant groups (triangulation of perspective).

The initial and final data sub-categories presented at the beginning of chapters six
to ten, contribute to the development of a transparent audit trail of the data analysis
process undertaken. Initial categories were finally abstracted to five over-arching
categories that adequately captured the nature and meaning of the findings emergent from
the data:

- The Culture of the Clinic
- Constructions of female sexuality after cancer treatment
Living with a changed sexual life after cancer
“Talking Sex” in the clinic
Assessing the sexual consequences of cancer therapy in practice

Following identification of these overarching data categories further data analysis was undertaken to triangulate data from participant observation with findings emerging from the in-depth interviews. Although findings from these different major data sets are presented separately in this thesis (Chapter five: Participant Observation Findings, Chapters six to ten: Interview Findings) for ease of comprehension, triangulation of data is evident from the cross referencing of data sources throughout the thesis findings chapters and in the discussion chapter (chapter 11).

3.8 Issues of Rigour in Ethnographic Research

It is normally inappropriate to evaluate the rigour of qualitative research using criteria developed to evaluate quantitative studies (Beck, 1993) as each set of criteria is based on different assumptions about the nature of knowledge generation and of measures of scientific rigour (Sandelowski, 1986, 1993; Beck, 1993). The number of criteria or models that have evolved to enable qualitative researchers to evaluate the rigour of their work has expanded particularly over the past two decades. Recently the need for explicit standards regarding what constitutes rigour in qualitative research evaluation was addressed by a study conducted by the National Centre for Social Research on behalf of the UK government. The authors of this report (Spencer et al. 2003) developed a framework for research evaluation based around four key principles that qualitative research should be:

- **Contributory** in advancing wider knowledge or understanding
- **Defensible** in design by providing a research strategy that can address the evaluation questions posed
- **Rigorous** in conduct through the systematic and transparent collection, analysis and interpretation of data
- **Credible** in claim through offering well-founded arguments about the significance of the data generated
In applying these evaluation principles to this study I have chosen qualitative criteria adapted from those proposed by Guba and Lincoln (1981), subsequently discussed by Sandelowski (1986) and operationalised by Beck (1993; see tables 3.8 to 3.10). Internal validity thus becomes credibility, external validity, fittingness and reliability is auditability (Beck, 1993).

As reflexivity is a core concept and process for the qualitative researcher that contributes directly to both the credibility and confirmability of qualitative research (Sandelowski, 1986) I will discuss this concept first.

3.8.1 Reflexivity in Ethnography

Although this chapter sub-section addresses the concept of reflexivity from a theoretical perspective, there is evidence throughout this thesis of my reflexive actions and commentary in making transparent the professional and personal beliefs that have shaped the processes and product of this research.

At the core of the concept of reflexivity is an understanding that researchers who choose to study the social world are themselves co-constructors of that world. In contrast to the stance of positivist researchers, those operating within an interpretive paradigm acknowledge and take account of their inevitable influence on the research field and the data generated. The processes involved in reflexivity make the researcher's socio-historical location and thus their values and beliefs transparent (Hammersley & Atkinson, 1995). Here the researcher is increasingly reflective and self-analytical in order to fully consider the use of self as a research instrument in the field of study (Allan, 1997). Reflexivity is an active process whereby the researcher explores the values and assumptions that constitute her inner world for the purpose of explaining (or accounting for) their influence on data generation, subsequent data analysis and interpretation (Allan, 1997; Arber, 2006). The processes of reflecting on one's thoughts and actions both during field work and during subsequent analysis can also be considered an indicator of researcher integrity and contributes towards the creation of a data audit trail in promoting research rigour within ethnographic practice (Arber, 2006). Reflexivity, however, is not solely an analytical muse that contributes to enhancing credibility and rigour within the research process; it is also a personal and professional process of critical awareness that contributes to every stage of the ethnographic 'product' construction (Bolam et al. 2003; Dowling, 2006).

Within the context of conducting ethnographic research shaped by feminist ideology the researcher takes steps to reduce the power differentials inherent to the
research process and "positions" herself in a reciprocal relationship with study participants (Dowling, 2006). Such reciprocity and collaboration between research participants and the researcher has the capacity to increase engagement, disclosure and thus intimacy within the research interview. These interpersonal conditions may be particularly important for the exploration of sensitive topics, such as sexuality, as they are likely to generate greater authenticity and depth of data than when distance is maintained in the participant – researcher relationship (Birch & Miller, 2000). However, as discussed previously in section 3.5.2, the researcher must then work reflexively in the interview to counter the risk of a more subtle form of participant exploitation taking place.

Within the context of this study I would also argue that research reflexivity and academic supervision can serve a similar purpose to the supervision undertaken by those offering psychological therapies, in that they "...can challenge the self-deceptions of researchers " (Dowling, 2006). These processes are central to both participant and researcher safety in addressing the emotional consequences of researching sensitive topics, such as sexuality, with a potentially vulnerable group of participants (Arber, 2006). Through reflexivity and engagement with my experience as a psychosexual therapist I was aware of the emotions generated in me and in others listening to or reading data extracts. There had been occasions when I was moved to tears in listening to both the women and partner's accounts of the changes they had experienced in their sexual lives after cancer. I was intrigued how I had been able to manage my emotions in research encounters with these women both during participant observation and interviews while adopting the roles of researcher, cancer nurse or (albeit occasionally and in a limited way) psychosexual therapist but in the privacy and solitude of data analysis was moved as a woman by what I heard and had begun to understand from participant's narratives.

As mentioned earlier in this chapter, thinking reflexively throughout this ethnography has continued into the writing of this research endeavour and is inevitably shaped by tensions arising from the real and imagined "audiences" I want to engage through the presentation of an authentic analysis and interpretation of the findings of this study (Day, 2002).

3.8.2 Credibility and the contribution of triangulation

The credibility of a qualitative study acknowledges the multiple "truths" inherent to both social constructionism (the underlying theoretical perspective of this study) and ethnography as a methodology. To achieve credibility the researcher must offer:
"...faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognize it from those descriptions or interpretations as their own." (Sandelowski, 1986, p.30).

Participant validation is recognised as one of the strategies that may be used to enhance the credibility of qualitative data. However, as discussed in section 3.5.3, participant validation was not undertaken in this study for ethical reasons. As can be seen in table 3.8, this study fulfilled the majority of operational criteria to achieve credibility including triangulation of data methods and sources, consistent evidence of researcher reflexivity and the inclusion of multiple data extracts to demonstrate the authenticity of subsequent data analysis and interpretation.

Table 3.8: Evaluation of the Credibility of Qualitative Research (Beck, 1993)

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did the researcher keep in-depth field notes regarding the researcher-participant relationships?</td>
<td></td>
</tr>
<tr>
<td>Were the effects of the researcher's presence on the nature of the data collected considered?</td>
<td></td>
</tr>
<tr>
<td>Did the researcher keep field-notes of their actions, interactions and subjective states during the investigation?</td>
<td></td>
</tr>
<tr>
<td>Did the researcher discuss their own behaviour and experiences in relation to the participant's experiences?</td>
<td></td>
</tr>
<tr>
<td>Did the researcher become so involved with the participants that they &quot;went native&quot; i.e. had difficulty in separating their own experiences from the participants?</td>
<td></td>
</tr>
<tr>
<td>Were multiple methods of data collection (triangulation) used to determine the congruence of the results among them?</td>
<td></td>
</tr>
<tr>
<td>Were the readers provided with rich excerpts from the transcripts or field-notes?</td>
<td></td>
</tr>
<tr>
<td>Did the researcher validate the findings with the participants?</td>
<td></td>
</tr>
<tr>
<td>Did the researcher search for negative instances of categories or discounting evidence for tentative constructs?</td>
<td></td>
</tr>
<tr>
<td>Were data analysis procedures reviewed by a judge panel to prevent researcher bias and selective inattention?</td>
<td></td>
</tr>
<tr>
<td>Do the readers view the findings as meaningful and applicable in terms of their own experiences?</td>
<td></td>
</tr>
</tbody>
</table>

Data coding and the creation of data categories and sub-categories were explored in detail with my academic supervisors and overlap, anomalies or inconsistencies identified and discussed prior to revision of the relevant category system. Flow diagrams of the category systems emergent from the data are also presented to enable the reader to verify the systematic nature of this categorisation process. As discussed in 3.6.4, field notes were kept in relation to both participant observation and interview elements of the study and made
reference to multiple domains of researcher reflexivity and perceived impact on both the participant-researcher relationships and nature and scope of data generated and collected. Triangulation as a term has been used to define two distinctly different, yet complementary, research purposes. Triangulation can be used to achieve data confirmation, what is often referred to as convergent validity, or it can be used to achieve a more through or comprehensive exploration of a phenomenon, particularly when that phenomenon is both complex and context dependent (Knafl & Breitmayer, 1991).

Sociologists adhering to a post-positivist tradition have argued that the concept of triangulation is based on a positivist bias (Silverman, 1985) as it contradicts the perspective of social action which concludes that each occurrence is socially constructed and thus unique. This view would also explain why convergence in triangulation rarely occurs (Patton, 1980). However, the argument in favour of triangulation is that it leads to different perspectives on the phenomenon being studied which are, in themselves, worthy of comprehension and interpretation (Denzin, 1989). Thus from a post-modern perspective, triangulation enables the multiple voices or multiple readings of social phenomena such as sexuality to be heard and seen.

This study used triangulation principally to explore the research topic in a comprehensive manner or for "completeness" although data analysis did specifically seek to identify elements of data corroboration where appropriate to do so. Hence data generated through participant observation and semi-structured interviews were combined to enable a between-methods triangulation of data (Denzin, 1989). Triangulation of these two different data collection methods were used to access different aspects of the research topic (Knafl & Breitmayer, 1991). Observation captured naturally occurring data about how, how often and under what observable circumstances health professionals enquired about women's sexual concerns, while in-depth interviews generated data that offered an explanation of participant's attitudes and beliefs about the clinical assessment of women's sexual well-being after cancer treatment. In addition, this study adopted triangulation of perspective or data source to address different elements of the research questions through the collection of data from different groups of research participants, namely women who had been treated with radiotherapy for a pelvic malignancy, male partners of those women and the different health professionals (doctors, nurses and therapy radiographers) responsible for the care and support of these women either during or after cancer treatment. The findings chapters that follow contain examples where triangulation of multiple perspectives have led to a more comprehensive understanding than any single piece of datum would have revealed.
3.8.3 Fittingness

In qualitative methodologies such as ethnography, research topics or phenomena are explored within their natural context and no attempts are made to control the conditions influencing emergent data. In evaluating the fittingness of this study (table 3.9) it is important to be able to demonstrate the extent to which the data generated through purposive sampling (3.6.6 to 3.6.8) are representative of both the “typical and atypical elements” of the participant’s experiences. Furthermore, this criterion also evaluates the extent to which the participant’s data collectively and adequately represents the phenomenon under study in satisfactorily answering the study’s research questions. One of my academic supervisors is also a cancer nurse and is familiar with the research contexts and some of the health professional participants of this study. In reviewing draft findings of this thesis she frequently commented on the apparent authenticity of the data extracts she read as they had a resonance with findings she had encountered in her own field research and clinical experience within those environments. The lay and professional readers of this study will also be in a position to consider the extent to which I have represented participant data that “fits” with the realities of participant’s experiences through research dissemination activities proposed in the distribution of both lay and professional summaries of the study findings and oral presentations to health professional participants at the respective research sites on conclusion of the study.

Table 3.9: Assessment of the Fittingness of Qualitative Research (Beck, 1993)

- Did the researchers establish the typicality of the participants and their responses?
- Did the researchers check for the representativeness of the data as a whole?
- Did the theoretical sampling result in a range of informants experiencing the phenomenon under study?
- Were the data made to appear more similar or congruent than they really were?
- Did the study results fit the data from which they were generated?

3.8.4 Auditability

The concept of auditability is often operationalised through the creation of an audit trail by which future researcher’s are able to “...clearly follow the ‘decision trail’ used by the investigator of the study.” (Sandelowski, 1986, p.33). This thesis chapter contains extensive detail of the decision making process I have followed at each stage of the research process and procedure. This would support another researcher in performing an
‘indirect replication’ of this study should they so wish. Auditability is also demonstrated through the researcher reflexivity documented throughout this thesis.

Table 3.10: Critiquing the Auditability of Qualitative Research (Beck, 1993)

- Was a tape recorder or other mechanical device used to record interviews?
- If a tape recorder was not used did the researcher compile their field-notes immediately after the interview or observation to increase accurate recall?
- Was an in-depth description of the strategies used to collect and analyse the data provided to the readers?
- Were the characteristics of the participants described and the process used to choose the participants?
- Were low inference descriptors, participant’s verbatim accounts, included to substantiate the categories developed during data analysis?
- Were the social, physical, and interpersonal contexts within which the data had been collected discussed by the researcher?
- Did the researcher specifically define the categories developed and also identify their theoretical antecedents?
- Did more than one researcher perform the theoretical coding?
- Did colleagues review the data to determine if they had identified the same categories and constructs as the researcher had?
- Could another investigator clearly follow the decision trail used by the researcher in the study?

3.9 Summary of Chapter

This chapter has explored ethnography as the chosen methodology for this research and has discussed different types of ethnography and their contribution to health care practice prior to defining this current study as a focused ethnography informed by the underlying philosophy of both critical and feminist ethnography. The principle ethnographic methods of participant observation and in-depth interviews have been outlined together with the approach taken in the analysis of ethnographic data. The ethical dimensions of conducting research on sensitive topics with potentially vulnerable participants have been addressed in this chapter and should not be considered a discrete methodological issue, but a thread that is woven throughout the conduct and delivery of this ethnographic ‘product’. Finally, after a detailed account of the research procedure followed for this study, the chapter concludes with a summary of appropriate measures of research rigour that can be used to evaluate this ethnography.
4.1 Participant Observation Data Sample

Participant observation at research site A commenced in September 2005 and completed in December 2005. Observation at research site B commenced October 2005 and completed in January 2006. Data collection continued until no new data categories were emergent in relation to the phenomenon under study: the discussion of female sexual difficulties by health care professionals in follow-up consultations with women who had received radiotherapy treatment for a pelvic malignancy.

I attended all NHS clinics where follow-up of my target population of women was to take place and this totalled five consultant clinics (three colorectal clinics and two gynaecological clinics) at site A, one nurse-led "on treatment review" clinic at site A and four consultant clinics (two colorectal clinics and two gynaecological clinics) at research site B. Although my initial intention was to observe clinics reviewing women with gynaecological (cervical and endometrial), colorectal (rectal and anal) and urological (bladder) malignancies it became evident that there were very few women with bladder cancer attending the urology clinics at either research site. I considered it unlikely that I would encounter many consultations with this small sub-group of women (with bladder cancer) where sexual issues were likely to be a clinical priority and therefore decided to focus on attending the gynaecological and colorectal clinics at both research sites. Scrutiny of the electronic patient records for women treated for bladder cancer by radical pelvic radiotherapy over a two year period revealed a total sample of 21 women, only two of whom met the inclusion criteria for this study.

In order to capture naturally occurring data, and to keep the researcher's influence on routine clinic process to a minimum, participant observation of consultations normally meant shadowing a specific clinician for the duration of that clinic. As a result of this strategy, I was present in a number of consultations where the patient's primary diagnosis or gender was out with the sampling criteria for my study. I observed a total of 141 individual consultations across 31 separate clinic sessions that included patients at all stages of their treatment journey post cancer diagnosis. Seventy-two (51.06%) observed consultations were subsequently excluded from data analysis as they did not meet the entry criteria (see Table 4.1 for summary).
Table 4.1: Primary Diagnoses for Patient Consultations Excluded from Study

<table>
<thead>
<tr>
<th>Primary Diagnosis</th>
<th>No. of Patients (n=72)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ovarian</td>
<td>13</td>
</tr>
<tr>
<td>Colon</td>
<td>12</td>
</tr>
<tr>
<td>Rectum (male)</td>
<td>11</td>
</tr>
<tr>
<td>Breast</td>
<td>9</td>
</tr>
<tr>
<td>Vagina</td>
<td>4</td>
</tr>
<tr>
<td>Caecum</td>
<td>4</td>
</tr>
<tr>
<td>Oesophagus</td>
<td>3</td>
</tr>
<tr>
<td>Pancreas</td>
<td>3</td>
</tr>
<tr>
<td>Gastric</td>
<td>2</td>
</tr>
<tr>
<td>Anus (male)</td>
<td>2</td>
</tr>
<tr>
<td>Lung</td>
<td>1</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>1</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>1</td>
</tr>
</tbody>
</table>

Analysis of the findings presented in chapter five therefore includes data from consultations with 69 (48.93%) women who had a primary diagnosis of anal, rectal, endometrial or cervical cancer receiving radical pelvic radiotherapy as one of their treatment modalities.

As there was no difference in patient or health care professional characteristics between research sites A and B the data are presented as a single data set even though observation took place in three separate outpatient departments (two at research site A and one at research site B).

4.1.1 Clinic and Health Care Professional Characteristics

I attended a total of 31 separate clinic sessions, the initial three sessions acting as a mechanism for piloting the participant observation method and my research role within the outpatient clinic environment. It was during this initial period that I developed an observation schedule (Appendix 7) to enable me to capture the necessary detail present within a busy clinical environment. The process of participant observation together with my reflections and interpretations as a nurse researcher was captured through detailed field notes recorded immediately on leaving the field at the end of the clinic.

Table 4.2 provides a summary of the types of clinics, designation and gender of clinicians in the observation sample during this four month period. A total of 24 / 31 clinic sessions acted as the sample for the 69 individual consultations included in this analysis.
In deciding on my sampling frame for the observation data I planned to sample both gynaecological and colorectal clinics and to ensure both follow-up and on-treatment review clinics were included in order to observe consultations at different time points in the women’s treatment journey. The on-treatment review clinics offer the observer an opportunity to consider the discussion topics deemed a priority for women during radiotherapy treatment. The follow-up clinics saw a minority of newly diagnosed patients in their pre-treatment phase but the majority of women attending the clinics were from six weeks up to 10 years post-treatment. This sampling strategy allowed me to observe whether or not the most frequently discussed consultation topics changed over time across the treatment journey. More specifically I hoped to identify when health professionals were most likely to discuss treatment-related sexual difficulties with women who had completed pelvic radiotherapy. I also observed different clinicians engaged in this patient review process to establish the potential influence of clinician gender, seniority / experience and background discipline (medicine versus nursing) on the nature of consultation content and process. The gender of the health care professionals observed was predominantly male (62.3%) including one consultant, one clinical research fellow and two specialist registrars. Consultations where the health care professional was female (37.7%) included four consultants, three specialist registrars, two staff nurses and one departmental sister.

### Table 4.2: Clinic Type, Clinician Designation and Gender

<table>
<thead>
<tr>
<th>No. of Clinics Observed</th>
<th>Clinic Type</th>
<th>Health Care Professionals Observed</th>
</tr>
</thead>
</table>
| 10                      | Gynaecological Follow Up      | 5 x Male Consultant  
1 x Female Consultant  
2 x Male Specialist Registrar  
1 x Female Specialist Registrar |
| 6                       | Colorectal Follow Up          | 2 x Female Consultant  
2 x Female Specialist Registrar  
2 x Male Clinical Research Fellow |
| 2                       | Mixed Diagnosis Follow Up     | 2 x Female Specialist Registrar |
| 4                       | Mixed On Treatment Review     | 1 x Female Specialist Registrar  
3 x Female Consultant |
| 2                       | Gynaecological On Treatment Review | 2 x Female Staff Nurses  
1 x Female Sister |
An aspect of the clinic process that can influence the nature and process of consultations was the extent to which clinics reviewed women from a limited diagnostic category (gynaecological or colorectal follow-up) compared to clinics where a more diverse range of diagnostic groups were included (mixed follow-up and on-treatment review clinics). It could be argued that mixed clinics present an additional challenge for clinicians where they have to be able not only to consider the needs of women at different stages of their treatment experience (mixed new patient, on-treatment review and follow-up) but also to consider those receiving different treatment modalities (chemotherapy, radiotherapy and hormone therapy) in the management of different primary diagnoses as illustrated in table 4.1. In a busy clinic environment it may prove difficult to retain a comprehensive and systematic approach to patient assessment where the clinical context for that assessment is constantly requiring revision and re-prioritisation. Hence it is conceivable that only core or shared elements of radiotherapy toxicity assessment were consistently used and recorded by clinicians.

### 4.1.2 Patient Characteristics

Table 4.3: Observed Consultations Data Summary: Patient Characteristics

<table>
<thead>
<tr>
<th>Patient Characteristic</th>
<th>No. / % (n = 69)</th>
<th>Patient Characteristic</th>
<th>No. / % (n = 69)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total no. of women with</td>
<td></td>
<td>Cervical Cancer</td>
<td></td>
</tr>
<tr>
<td>gynaecological diagnosis</td>
<td>50 (72.5%)</td>
<td>Endometrial Cancer</td>
<td>20 (29%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>30 (43.5%)</td>
</tr>
<tr>
<td>Total no. of women with</td>
<td></td>
<td>Anal Cancer</td>
<td></td>
</tr>
<tr>
<td>non-gynaecological diagnosis</td>
<td>19 (27.5%)</td>
<td>Rectal Cancer</td>
<td>5 (7.2%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>14 (20.3%)</td>
</tr>
<tr>
<td>Clinical Stage:</td>
<td></td>
<td>Age of woman &lt;= 60 years</td>
<td></td>
</tr>
<tr>
<td>I / II</td>
<td>29 (43.3%)</td>
<td>Age of woman &gt; 60 years</td>
<td>32 (46.4%)</td>
</tr>
<tr>
<td>III / IV</td>
<td>38 (56.7%)</td>
<td></td>
<td>37 (53.6%)</td>
</tr>
<tr>
<td>Treatment Type:</td>
<td></td>
<td>Time Post RT &lt;6 months</td>
<td></td>
</tr>
<tr>
<td>CTRT</td>
<td>31 (44.9%)</td>
<td>Time Post RT 6-11 months</td>
<td>31 (44.9%)</td>
</tr>
<tr>
<td>EBBRA</td>
<td>32 (46.4%)</td>
<td>Time Post RT &gt;/= 12 months</td>
<td>9 (13%)</td>
</tr>
<tr>
<td>EBRT</td>
<td>6 (8.7%)</td>
<td></td>
<td>29 (42%)</td>
</tr>
<tr>
<td>Relationship Status:</td>
<td></td>
<td>Woman accompanied at consultation:</td>
<td></td>
</tr>
<tr>
<td>Partner</td>
<td>48 (69.6%)</td>
<td>Yes</td>
<td>30 (43.5%)</td>
</tr>
<tr>
<td>No Partner</td>
<td>14 (20.3%)</td>
<td>No</td>
<td>39 (56.5%)</td>
</tr>
</tbody>
</table>

*Key: CTRT: Concurrent chemo-radiotherapy
EBRT: External Beam Pelvic Radiotherapy
EBBRA: External beam radiotherapy & vaginal brachytherapy
Table 4.3 provides a summary of the patient characteristics relevant to the analysis of the 69 observed health professional consultations with women. As can be seen from this table, the majority of women (72.5%) had a primary diagnosis of either cervical or endometrial cancer and were aged over 60 years (53.6%). This sample of consultations is broadly representative of the age group of women affected by these types of cancer in the UK population, although women with gynaecological cancer diagnoses are over represented. This sample of consultations represents the follow-up experience of women with both early stage (43.3% clinical stage I or II) and late stage (56.7% clinical stage III or IV) disease who received radiotherapy in the management of their illness. The use of chemo-radiotherapy (44.9% CTRT) or combined external beam and brachytherapy (46.4% EBBRA) as an adjunct to surgical management pre- or post-operatively reflects contemporary multi-modality cancer management. This sample of observed consultations offered the opportunity to review the priority topics discussed in health care consultations at different time points in the women's cancer treatment journey; including 16 women (23.2%) seen during radiotherapy and women who were receiving medical follow-up (n = 19, 27.5%) up to 24 months post-completion of treatment. The majority of women had a current partner (69.6%) although details of relationship status were missing for seven (10.1%) women in the consultations observed. Details of relationship status were taken from the women's medical records (paper or electronic) and all women were recorded as being in a heterosexual relationship.

4.2 Interview Participant Data Sample

Reflecting on my initial sampling strategy (section 3.6.7) for the interview component of this study I can see that not only was the sample over ambitious in scope / size but the sampling approach was also likely to be difficult to operationalise in the context of a study where the research topic was sensitive and participant recruitment entirely voluntary. It could also be argued that my sampling strategy had been influenced by the dominant research paradigm (positivism) within my professional/ clinical background and subsequent COREC documentation for research ethics.

As discussed in section 3.6.8, through purposive sampling I took steps to ensure that the range of women and health professionals invited to participate in the study were appropriate for the research aims and questions to be addressed through this
ethnography. The male partners who contributed to this study were inevitably “selected” by the women who gave permission to approach them and their own decision whether or not to take part.

4.2.1 Characteristics of the women

Following scrutiny of electronic patient records a total sample of 77 women (n = 55 women with cervical or endometrial cancer and 22 women with rectal, anal or bladder cancer) were sent invitation letters to participate in study interviews. In addition, some women were approached by letter following opportunistic identification of suitable study participants during the period of participant observation in the follow-up clinics. This latter strategy was particularly helpful in recruiting women who had completed their pelvic radiotherapy three to six months previously who were not on the patient lists generated by the Trust.

Table 4.4 offers a summary of the numbers of women who finally agreed to take part in this study as a proportion of the sample of women approached. The overall participation rate of 31.2% of the eligible study sample may be considered low within a quantitative study, but this sample does include women from each of the proposed primary diagnostic groups.

<table>
<thead>
<tr>
<th>Primary Diagnosis</th>
<th>Total Eligible Sample</th>
<th>Study Refusals</th>
<th>Study Non-Response</th>
<th>Study Participation Rate / %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anal Cancer</td>
<td>9</td>
<td>3</td>
<td>3</td>
<td>3 / 33.3%</td>
</tr>
<tr>
<td>Bladder Cancer</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1 / 50%</td>
</tr>
<tr>
<td>Rectal Cancer</td>
<td>11</td>
<td>3</td>
<td>4</td>
<td>4 / 36.3%</td>
</tr>
<tr>
<td>Cervical Cancer</td>
<td>25</td>
<td>0</td>
<td>16</td>
<td>9 / 36%</td>
</tr>
<tr>
<td>Endometrial Cancer</td>
<td>30</td>
<td>11</td>
<td>12</td>
<td>7 / 23.3%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>77</td>
<td>17</td>
<td>36</td>
<td>24 / 31.2%</td>
</tr>
</tbody>
</table>

Of the 17 women who sent back their reply slips to indicate they did not wish to participate in the study, seven gave a reason for their refusal either in writing, by email or following a request for me to contact them to discuss the study over the phone.

Six of the women stated they had declined to participate as they had not been sexually active with their partner for some years and did not anticipate this changing. Four of the women indicated that this sexual “inactivity” was unrelated to their cancer treatment. Three
of these women stated that they were supportive of the topic of the research and would have been willing to take part had their personal circumstances been different. One woman expressed distress at the prospect of having to talk about her sexual life and was reassured that this fact alone would exclude her from the study on ethical grounds, while another woman expressed regret at not being able to participate because of a "domestic emergency". It was interesting to note that each of these women appeared to have defined "sexual activity" solely as heterosexual intercourse despite my attempts to use inclusive language in the invitation letter and study information sheet to include women in same sex relationships and those engaging in other coital and non-coital forms of sexual expression (Appendices 8-9).

In adopting the principles of purposive sampling it was important for me to ensure that the women who agreed to take part in the study had sufficiently diverse personal and illness characteristics to address the research aims and contribute to answering the key research questions of this study. Tables 4.5 and 4.6 compare the known patient characteristics of study participant and non-participant groups. While acknowledging the voluntary nature of study recruitment, it was important to me that, as far as possible, the sample of women who took part in this study could be said to be broadly representative of the characteristics known about the women who refused to take part in the study. Clearly in exploring the potential sampling bias present in this study it was impossible to ascertain as to whether or not the sexual beliefs, relative importance of sexuality and nature / range of post-treatment sexual changes experienced by women would be similar in both the study participant and non-participant groups. However, it was possible to compare characteristics that were known to influence women's beliefs and attitudes about sexuality as well as to ascertain whether or not the women who had agreed to take part in the study differed in any substantial ways from those who refused to participate.

As can be seen from table 4.5, although women with endometrial cancer were slightly under-represented in the study participant group, women from all relevant primary diagnostic groups were included in this study. Both groups of women (participants versus non-participants) were similar in relation to clinical stage of the woman's illness, women's age, menopausal status, and the presence of relevant co-morbidities.

The dominant ethnicity in both groups was white British, although the patient sample did include one woman from Afghanistan and one woman who was a black Zimbabwean. The dominant religion followed in both groups was Church of England or
Roman Catholic. Twelve out of the 24 study participants described themselves as currently "practising" their religion.

Table 4.5: Comparative Summary of Demographic Details of Non-Participants and Study Participants

<table>
<thead>
<tr>
<th>Patient Characteristics</th>
<th>Non-Participants (n = 53)</th>
<th>Study Participants (n = 24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cervical Cancer</td>
<td>16</td>
<td>9</td>
</tr>
<tr>
<td>Endometrial Cancer</td>
<td>23</td>
<td>7</td>
</tr>
<tr>
<td>Anal Cancer</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Rectal Cancer</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Bladder Cancer</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Age of woman &lt;= 60 years</td>
<td>34</td>
<td>16</td>
</tr>
<tr>
<td>Age of woman &gt; 60 years</td>
<td>19</td>
<td>8</td>
</tr>
<tr>
<td>Clinical Stage: I / II</td>
<td>39</td>
<td>18</td>
</tr>
<tr>
<td>Clinical Stage III / IV</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>Ethnicity:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>39</td>
<td>19</td>
</tr>
<tr>
<td>Black British</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>White (other)</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Asian (other)</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Black (other)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Not Known</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Religion:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Church of England</td>
<td>23</td>
<td>11</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>Baptist</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Christian</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Methodist</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Muslim</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Hindu</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Atheist</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>None / Not Known</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>Relationship Status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current Partner</td>
<td>43</td>
<td>19</td>
</tr>
<tr>
<td>No Partner</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Not Known</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Co-Morbidities:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Depression</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>9*</td>
<td>6**</td>
</tr>
<tr>
<td>Smoker</td>
<td>Not known</td>
<td>5</td>
</tr>
</tbody>
</table>

* Co-morbidities in non-participants included: Arthritis (n = 1), Hypothyroidism (n = 2), Bladder Dysfunction (n = 2), Bowel Frequency (n = 2), Faecal Leakage (n = 1), Fatigue (n = 1)

** Co-morbidities in study participants included: Hypothyroidism (n = 1), Counselling re diagnosis adjustment (n = 1), Anti-depressant Therapy (n = 1), Anxiety (n = 1) Lower limb / genital lymphoedema (n = 2), Fatigue (n = 1), Faecal Urgency (n = 1), HIV on triple therapy (n = 1)

135
The study participant group recruited a higher proportion of women (five out of 24, compared to five out of 53 women) who were not in a current relationship perhaps indicating that sexuality can be important to women irrespective of their relationship status.

Table 4.6 summarises the women’s treatment and sexual health related characteristics recorded in the electronic patient records.

**Table 4.6: Comparative Summary of Demographic Details of Non-Participants and Study Participants: Treatment and Sexual Health Characteristics**

<table>
<thead>
<tr>
<th>Patient Characteristics</th>
<th>Non- Participants (n = 53)</th>
<th>Study Participants (n = 24)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Treatment Summary:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CTRT</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>CTRT + BRA</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>EBBRA</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>EBBRA + CT</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>TAH + CTRT</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>TAH + EBRT</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>TRA + CTRT</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>TAH + EBBRA</td>
<td>20</td>
<td>7</td>
</tr>
<tr>
<td>CTRT + AP resection</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>CTRT + ANT resection</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>EBRT (Electrons)</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td><strong>Time Post Pelvic RT:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3-5 months</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>6-9 months</td>
<td>15</td>
<td>4</td>
</tr>
<tr>
<td>10-18 months</td>
<td>15</td>
<td>12</td>
</tr>
<tr>
<td>20-31 months</td>
<td>19</td>
<td>7</td>
</tr>
<tr>
<td><strong>Menopausal Status prior to RT:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-menopausal</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>Peri-menopausal</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Post-menopausal</td>
<td>35</td>
<td>12</td>
</tr>
<tr>
<td><strong>Use of Vaginal Dilators Recorded:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>17</td>
<td>10</td>
</tr>
<tr>
<td>NO</td>
<td>36</td>
<td>14</td>
</tr>
<tr>
<td><strong>Vaginal Toxicity Recorded:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>21</td>
<td>6</td>
</tr>
<tr>
<td>NO</td>
<td>32</td>
<td>18</td>
</tr>
<tr>
<td><strong>Sexual Concerns Recorded Post-RT:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>16</td>
<td>12</td>
</tr>
<tr>
<td>NO</td>
<td>37</td>
<td>12</td>
</tr>
</tbody>
</table>

* No. of private patients participating = 6 / 24 (25%) of sample

The study participant group contained comparatively fewer women who were less than nine months or greater than 20 months post treatment completion. The majority of women who agreed to take part in the study were approximately 10 -18 months post-treatment and the range of treatments employed was similar in each group. Scrutiny of the electronic patient records of both groups of women indicated that vaginal toxicity was recorded in one third of participant's records and in two thirds of non-participants. Recording of whether or not women were using their vaginal dilators was recorded in 10 out of 24 study participants compared to only 17 out of 53 non-participants. In relation to the recording of post-treatment sexual concerns, 50% of study participants had a sexual concern recorded in their electronic patient record compared to only 16 out of 53 non-participants. With regards to these latter patient characteristics, however, routine recording of such information does not tend to be reliable and so the absence of such information could also represent data omissions.

In comparing the sample of women who were present in the observation element of this study with those who volunteered to take part in the research interviews the patient characteristics are similar with the exception of three factors. Women with cervical cancer represented a higher proportion of women who took part in the interview element of the study (37.5% compared to only 29% in the clinic observation) and women with endometrial cancer represented a smaller proportion of women (29.2% compared to 43.5% of women in the clinic observation). Furthermore, the women who took part in study interviews were a younger group overall with 66.6% of the interview sample aged 60 years or younger compared to only 46.4% of women in that age group in the clinic observation. It was also interesting to note that women who were less than six months post-treatment were under-represented in the study interview sample and those who were over 12 months post treatment completion over-represented compared to those women encountered during the participant observation period in the follow-up clinics. This pattern of participation may reflect the time period after treatment when women have recovered sufficiently from acute side-effects to consider sexual expression relevant to their lives again.

One final element of demographic data collected prior to commencement of the women's research interviews was whether or not the woman was currently sexually active. This information was rarely recorded in the women's electronic patient records. Table 4.7 provides a summary of the level and type of sexual expression women were engaged in at the time of their study interviews. As will be seen from the findings discussed in chapter eight, however, the fact that a woman has resumed sexual
intercourse does not tell us whether or not her sexual recovery is satisfactory, it merely indicates that she has attempted sexual intercourse since treatment completion.

Table 4.7: Post-Treatment Sexual Activity in Patient Interview Participants

<table>
<thead>
<tr>
<th>Current Sexual Activity</th>
<th>Cervical (n = 9)</th>
<th>Endometrial (n = 7)</th>
<th>Rectal (n = 4)</th>
<th>Anal (n = 3)</th>
<th>Bladder (n = 1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaginal Intercourse</td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Self-stimulation / vibrator</td>
<td>2 (2 x no partner)</td>
<td>1</td>
<td>0</td>
<td>1 (no partner)</td>
<td>1 (no partner)</td>
</tr>
<tr>
<td>No sexual expression</td>
<td>3</td>
<td>3 (1 x no partner)</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

Another interesting feature of this information is the small number of women (n = 5) who engaged in masturbation as their sexual expression, particularly where they did not have a current partner. This indicates that women may still be engaged in sexual expression without a partner or where sexual intercourse has not yet been possible or desired. While I acknowledge that this sample of 24 women are self-selecting and may therefore represent a source of sampling bias, it is interesting to note that eight women with a current partner were not engaged in any sexual expression at the time of their involvement in this study. Women’s sexual recovery after cancer treatment is discussed in some detail within chapter eight: Living with a changed sexual life after cancer.

4.2.2 Characteristics of the partners

Partners of patient participants in the study were recruited following permission to approach them from their female partner (n = 19). Permission was granted by 15 out of 19 women (78.9%) at the time of their study interview, resulting in a total eligible partner sample of 15 men. Five out of 24 women (20.8%) did not have a current partner and four women (16.6%) refused permission to approach their partner about the study.

Partners were contacted by letter sent from the medical consultant caring for the woman who had already been interviewed for the study. Of the total number of male partners contacted by letter five agreed to participate, one returned their reply slip stating they did not wish to take part and nine men did not reply. No reminder letters were sent to partners. This participation level represents 33.3% (5/15) of the total sample available. Table 4.8 provides a summary of the demographic details of the five male partners who took part in this study.
Table 4.8 Demographic Details of Partner Interview Participants

<table>
<thead>
<tr>
<th>Demographic Details</th>
<th>Participant Nos.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender:</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
</tr>
<tr>
<td>Female</td>
<td>0</td>
</tr>
<tr>
<td>Age:</td>
<td></td>
</tr>
<tr>
<td>( \leq 60 ) years</td>
<td>2</td>
</tr>
<tr>
<td>( &gt; 60 ) years</td>
<td>3</td>
</tr>
<tr>
<td>Ethnicity:</td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>5</td>
</tr>
<tr>
<td>Religion:</td>
<td></td>
</tr>
<tr>
<td>Church of England</td>
<td>2</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>1</td>
</tr>
<tr>
<td>Agnostic</td>
<td>1</td>
</tr>
<tr>
<td>None</td>
<td>0</td>
</tr>
<tr>
<td>Relevant Medical History:</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>3</td>
</tr>
<tr>
<td>Benign Prostatic Hypertrophy</td>
<td>1</td>
</tr>
<tr>
<td>* Hypertension</td>
<td>1</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>1</td>
</tr>
<tr>
<td>Sexual Concerns prior to partner’s diagnosis:</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td>Co-existing sexual difficulty in the male partner:</td>
<td></td>
</tr>
<tr>
<td>ED</td>
<td>1</td>
</tr>
<tr>
<td>Low sexual interest</td>
<td>2</td>
</tr>
<tr>
<td>Sexual abstinence due to partner’s vaginal bleeding</td>
<td>1</td>
</tr>
<tr>
<td>Treatment sought for sexual difficulty:</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1 (GP for ED)</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
</tr>
</tbody>
</table>

* One man had both hypertension and cardiovascular disease.

As can be seen from table 4.8, one of the men interviewed (PTNR01) had developed erectile difficulties (ED) during the first year following his wife’s (PT09) treatment, despite the couple having had an initial satisfactory sexual recovery. Two of the men interviewed reported awareness of a reduction in their own sexual desire as a direct result of not being able to resume sexual intimacy and intercourse after their wife’s treatment completion. The impact of women’s changed sexual lives on the partner is discussed in detail within section 8.8.

4.2.3 Characteristics of the health professionals

Health care professionals present in the medical follow-up clinics (sites A & B) and nurse-led radiotherapy on-treatment review clinics (site A) during participant observation data collection were approached directly and asked to take part in the interview element of this study in order to create the opportunity for data triangulation. Recruiting health professionals for interview who had been observed in their clinical setting would enable me to compare findings from naturally occurring data (observed clinic consultations) with those offered by health professionals at the time of their interviews. Although some of the
medical staff present during participant observation had moved to different hospital Trusts by the time recruitment for interviews was due to take place, it was possible to contact them by phone at their new Trust setting. The four clinical nurse specialists and two therapy radiographers involved in the support and “feminine care” provision for women receiving pelvic radiotherapy were contacted by email as they were not routinely present in the follow-up clinics.

A total of 21 health professionals were approached to take part in interviews and only one specialist registrar from site B did not reply to contact made by phone / email. No health professionals approached to take part refused to be involved.

Table 4.9: Demographic Details of Health Care Professional Interview Participants

<table>
<thead>
<tr>
<th>Demographic Details</th>
<th>Nos.</th>
<th>Demographic Details</th>
<th>Nos.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender: Female</td>
<td>16</td>
<td>Male</td>
<td>4</td>
</tr>
<tr>
<td>Age: &lt; 30 years</td>
<td>1</td>
<td>30-40 years</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>41-50 years</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>51-60 years</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt; 60 years</td>
<td>1</td>
</tr>
<tr>
<td>No. of years post-qualification: &lt;5 yrs</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5-10 yrs</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>11-20 yrs</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&lt;20 yrs</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Ethnicity: White British</td>
<td>14</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black British</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White (other)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of years in oncology: &lt;3 yrs</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3-5 yrs</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6-10 yrs</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; 10 yrs</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Religion: Protestant / Christian</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hindu</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Methodist</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agnostic</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of years in clinical oncology: &lt; 3 yrs</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3-5 yrs</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6-10 yrs</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; 10 yrs</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Practising: YES</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NO</td>
<td>12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Profession / Grade: Medical Consultant</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specialist Registrar</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Research Fellow</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Nurse Specialist</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff Nurse</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapy Radiographer</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-qualifying education / training: Women’s Health / Gynaecology</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual Health / Family Planning</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual Counselling</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Health</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological Counselling</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication Training</td>
<td>12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No relevant additional training</td>
<td>7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

As can be seen from the summary of health professional demographic details in table 4.9, the sample included representation from all staff groups involved in the care of
women receiving pelvic radiotherapy across both research sites. Personal and professional characteristics of health professionals recorded for this study were those thought to influence the practitioner's willingness to discuss treatment-related sexual difficulties in the clinical setting. These characteristics are discussed in the literature reviewed in chapter two and include the practitioner's age, gender, ethnicity, religious beliefs and religiosity, professional experience and specialist post-qualifying education and training in relevant fields such as women's health, gynaecology, family planning, sexual health or counselling, mental health, psychological counselling / therapy and communication skills training.

The majority of health professional participants were female, white British, aged less than fifty years and although the majority stated belonging to a particular faith, only eight described themselves as currently "practising" a religion. There were 11 medical staff, seven nurses and two therapy radiographers interviewed for this study. All had been qualified for longer than five years and the majority had spent over three years working in oncology and radiotherapy practice. Analysis of the demographic details of HCP participants revealed that very few (four out of 11 doctors in the study) of the medical staff had received any specialist post-qualifying education in a speciality relevant to knowledge and skills development regarding the assessment and management of female sexual difficulties after cancer treatment. Seven medical staff (four consultants, two specialist registrars, one clinical research fellow) had not received any relevant post-qualifying education and training on this topic.

The most common form of post-qualifying education received by practitioners in this study was a brief communication skills training (one to three days) but, as discussed in section 9.1, this did not include skills development in relation to talking about sensitive topics such as sexuality but tended to focus largely on communication approaches to "breaking bad news".

Where sexual health or counselling training was mentioned by practitioners this normally constituted brief in-service education or conferences of approximately one half day or one day duration.
4.3 Data sets and emergent categories

Once all of the interview participants had been recruited and interviewed it was possible to identify links between the three separate interview data sets (women, partners and health professionals) whereby doctors and nurses who had been directly involved in women's treatment and care could be identified together with women's partners who took part. This created 24 linked data sets or "cases" (see appendix 19), including five that represented the perspectives of all three participant groups. These data sets were scrutinised for transcript evidence of corroboration or contradiction, particularly between views expressed by women and their partners regarding the impact of cancer treatment on sexual well-being. Furthermore, corroboration between interview data sets and observation data were explored in order to enhance rigour in data analysis and interpretation through the process of data triangulation by identifying cross-cutting categories in the data. As will be seen in the interview findings presented in chapters six to ten, where possible examples of data corroboration have been sought, together with examples where there are data discrepancies.

In presenting a large and complex set of data I have decided to present the findings from participant observation (chapter five) separately from the findings emerging from interview transcripts (chapters six to ten). Where appropriate I have cross referenced findings in the interview data to corroborating or conflicting data present in the participant observation data analysis. The findings chapters which follow are structured around the categories and sub-categories emerging from interview data analysis.
Chapter 5: Participant Observation Findings

As discussed previously, there are two principal sources of data that inform this ethnographic study: in-depth interviews with women, partners and health professionals and observation of health care professional consultations with women who were receiving / had received pelvic radiotherapy for a gynaecological or non-gynaecological malignancy. This chapter presents the findings from analysis of participant observation data only using SPSS version 14.0.

5.1 Content Analysis of Health Care Consultations

In observing consultations between health care professionals and women who had received pelvic radiotherapy I was interested both in the content of these discussions and to ascertain who normally set and led the communication agenda. It is interesting to note that the literature related to health professional – patient communication about sexuality reviewed in sections 2.4.1 and 2.4.3 did not include a comprehensive sociological analysis of the structural influences and power dynamics that serve to maintain dominant patterns of unilateral communication in the context of medical consultations. Yet this study found that consultations were usually structured and the agenda led by health care professionals. Women tended to restrict their contributions to answering questions put to them by the particular health professional.

Figure 5.1 provides a summary of the range of topics raised within the 69 observed consultations. The most frequently raised topics were related to the acute and late effects of pelvic radiotherapy on both the bowel and the bladder. Bowel and bladder toxicity monitoring was present in 81% and 70% of consultations respectively, although no formal scale or method of toxicity recording was used to note these toxicities unless the woman was enrolled in a clinical trial where specific toxicity data sheets were completed. Six out of the 19 women with anal or rectal cancer were taking part in clinical trials of chemoradiation treatment at the time of this study, representing 8.7% of the total number of individual consultations observed. Health care professionals (HCP) raised the topic of bowel symptoms in 76.8% of consultations, with women raising the topic in 18.8% of consultations.
With regard to bladder symptoms HCPs raised this topic in 65.2% of consultations compared to 4.3% of consultations where the topic was raised by the woman (n = 2) or a partner (n = 1) present in the consultation. There were 60 other topics raised, the majority of which were physical side effects of the women's treatment, during 39 / 69 (57%) of the consultations observed. HCPs raised these topics 62% of the time, with women raising the topic on 23 (38%) occasions. These other symptoms ranged from discussions about anorexia, nausea and dietary intake or weight gain, to concerns about fatigue, general weakness, mobility, lymphoedema and continence management.

Psychological or social aspects of the women's illness and treatment were discussed in 42% (n = 29) of the consultations observed and varied from in-depth discussion of the family implications of disease progression or recurrence to making a brief enquiry as to whether or not the woman had returned to work after treatment completion. Women raised psychological or social issues in 14.5% of observed consultations, compared to 27.5% where HCPs raised this topic and in 58% of observed consultations no psychological or social content was present at all.
Health care professionals were dominant in leading topic discussions for all of the 13 topics summarised in figure 5.1, with women raising individual topics with their treatment team in only zero to 14.5% of consultations.

5.2 Discussion of Vaginal Toxicity, Vaginal Dilator Use and Treatment Induced Menopause in Women’s Consultations with Health Care Professionals

Vaginal toxicity associated with pelvic radiotherapy as an overarching discussion topic occurred in 29 (42%) of the 69 consultations observed. During consultations one or more specific vaginal symptoms were either elicited by verbal questioning or through vaginal examination. Vaginal examination was a routine element of medical review in the gynaecological clinics but performed only where clinically indicated by active symptoms in the colorectal clinics observed and never performed in the nurse-led radiotherapy review clinics.

As can be seen from figure 5.2, vaginal bleeding was the symptom most commonly raised in a total of 17 consultations by both HCPs (n = 13 / 18.8%) and women (n = 4 / 5.8%).

Figure 5.2: Types of Vaginal Toxicity Discussed in Consultations
Despite their prominence in the biomedical literature as commonly occurring toxicities after pelvic radiotherapy, vaginal stenosis, shortening and dryness were only discussed in 11 (15.9%), nine (13%) and six (7.2%) observed consultations respectively. Manifestations of late radiation toxicity in the vagina such as telangectasia or ulceration were usually discussed with women only when they resulted in vaginal bleeding, otherwise they were simply recorded in the women’s medical records. Fourteen women with vaginal symptoms had completed treatment twelve or more months previously, five women had completed treatment six to eleven months previously and ten women had completed treatment less than six months previously. There was no statistically significant relationship between the discussion of vaginal symptoms and the time elapsed since women had completed their radiotherapy treatment, although vaginal symptoms were prevalent in 14 / 29 (48.2%), 5 / 9 (55.5%) and 10 / 31 (32.2%) of women at these time points post-treatment respectively.

Discussion of vaginal dilator provision and use occurred in 16 (23.2%) consultations, being raised predominantly by HCPs (n = 11 / 15.9%). The provision of vaginal dilators as a prophylactic intervention to reduce the likelihood of developing vaginal stenosis and shortening associated with pelvic radiotherapy was standard practice at both research sites. At research site A, vaginal dilators were predominantly provided by nursing staff based in either the radiotherapy department or in the private patient's outpatient department, while at research site B they were provided by therapy radiographers. Written information on the use of vaginal dilators and what was referred to as “feminine care” was supposed to be offered to all women having radical pelvic irradiation. It is therefore interesting to note that discussion of the provision and use of vaginal dilators was absent from the majority of observed medical consultations (n = 53 / 76.8%).

In order to determine whether there was an association between discussion of vaginal toxicity in consultations and subsequent discussion of the provision and use of vaginal dilators Pearson's Chi-Square test was used to analyse a 2 x 2 contingency table in order to explore the relationship between these two sets of nominal data (see Table 5.1). Using Pearson’s Chi-Square and Fisher's Exact test there was a statistically significant difference at the one per cent level ($\chi^2 = 22.870$, df = 1, $p = 0.000$) between these two variables. In only one consultation was there a discussion of dilator provision where vaginal toxicity had not been raised in the consultation, compared to 15 occasions where the two topics were discussed within the same consultation. The single consultation (Gynae. 29.3) where the use of dilators was discussed in the absence of any mention of
vaginal toxicity was with a woman aged 71-80 years in an on-treatment review clinic where
discussion of the post-treatment use of vaginal dilators had been initiated by the woman.

Table 5.1: Summary of Dilator Use Discussions X Summary of any vaginal

toxicity symptom present / absent in consultations

<table>
<thead>
<tr>
<th>Summary of Dilator Use Discussions</th>
<th>Summary of any vaginal toxicity symptom present / absent in consultation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes 15</td>
</tr>
<tr>
<td>No</td>
<td>Yes 14</td>
</tr>
<tr>
<td>Total</td>
<td>29</td>
</tr>
</tbody>
</table>

* $\chi^2 = 22.870$, df = 1, p = 0.000, Fisher's Exact test p = 0.000

Discussion of treatment induced menopause and its management was a topic discussed in
nine (13%) consultations, raised predominantly by HCPs (n = 7 / 10.1%). While this
number is low it should be noted that in 37 / 69 (53.6%) consultations the woman was
already naturally post-menopausal at the time of her cancer treatment, resulting in
omission of this topic within 23 (33.3%) consultations where the woman was post-
menopausal as a direct result of her cancer therapy.

One further element of patient management that was explored through participant
observation was to ascertain whether or not the discussion of vaginal toxicity, menopause
or sexual issues would lead to onward referral where appropriate. Referrals resulting from
such discussions were uncommon, occurring in a total of eight out of 69 (11.6%)
consultations. Women were referred to the radiotherapy nursing service on seven (10.1%)
occasions, to a clinical nurse specialist in gynae-oncology on one (1.4%) and to a
woman’s GP on one (1.4%) occasion. Closer exploration of these findings revealed that
the sole referral to the clinical nurse specialist was for discussion of concerns regarding
treatment induced menopause, as neither vaginal toxicity nor sexual issues had been
discussed with this woman (31-40 years of age, cervical cancer diagnosis) during her
observed consultation. The woman who was referred to her GP (41-50 years of age, anal
cancer diagnosis) had also experienced treatment induced menopause and was referred
to have hormone replacement therapy (HRT) discussed and prescribed, she was also
referred to the radiotherapy department nursing service for re-issue of vaginal dilators
having developed a degree of vaginal stenosis that was causing her current difficulty in her sexual relationship. The remaining six women were all referred to the radiotherapy department nursing service for the provision and / or further discussion of vaginal dilators as their consultations had raised both vaginal toxicity and sexual issues.

5.3 Discussion of Sexual Issues in Women’s Consultations with Health Care Professionals

Enquiry or comment about a woman’s sexual well-being was normally introduced by health care professionals asking a direct question such as: “Are you sexually active at present?” This trigger question could then lead on to additional probes dependent on the response to the initial enquiry.

As can be seen in figure 5.3, sexual issues were discussed in a total of 17 (24.6%) consultations, with health care professionals raising this topic on 11 (15.9%) occasions and by women on a further six (8.7%) occasions.

Figure 5.3: Sexual Issues Raised in Consultations

The range of sexual topics discussed during consultations between women and their treatment team was relatively narrow, with reduced sexual interest or desire (n = 7 / 10.1%) and reduced frequency of intercourse (n = 5 / 7.2%) featuring more often than
discussion of dyspareunia (n = 4 / 5.8%). Discussion of reduced sexual interest, reduced
frequency of sexual intercourse and the impact of sexual changes on the partner were all
raised more frequently by the women themselves when compared with health care
professionals, although the overall frequency of such discussions in consultations
remained low.

Changes in orgasmic capacity or sensation were not discussed nor was there any
enquiry as to whether or not treatment had influenced women’s degree of sexual
satisfaction. Discussion of sexual issues normally focused on the woman’s view of her
altered sexual function with no reference to her sexual relationship other than to ascertain
that there was a current partner. Concerns relating to partner adjustment to changes in the
couple’s sexual relationship arising from the woman’s cancer treatment were raised by two
(2.9%) of the women. Interview findings related to the nature and meaning of changes in
women’s sexual lives after cancer treatment is discussed in chapter eight: Living with a
changed sexual life after cancer.

In addition to any consideration of the frequency and nature of sexual issues
discussed, I was also interested to ascertain whether or not discussion of sexual issues in
observed consultations was prompted or blocked by specific health professional, patient,
ilness or treatment related factors. In order to explore relationships between these
consultation attributes or variables a number of cross-tabulations were performed and
subjected to statistical analysis using Pearson’s Chi-Square test. Consultation factors
where there was no statistically significant relationship demonstrated are summarised in
table 5.2.

Table 5.2: Consultation factors where there was No statistically significant
relationship with the discussion of sexual issues in observed
consultations

<table>
<thead>
<tr>
<th>Health Care Professional Factors</th>
<th>Patient Factors</th>
<th>Illness / Treatment Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender of health care professional</td>
<td>Relationship Status</td>
<td>Primary Diagnosis</td>
</tr>
<tr>
<td></td>
<td>Accompanied at consultation</td>
<td>Time elapsed post-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Psychosocial issues</td>
</tr>
<tr>
<td></td>
<td></td>
<td>discussed in consultation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total number of topics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>discussed in consultation</td>
</tr>
</tbody>
</table>

Although the total number of female HCPs was low (n = 26 / 37.7%) the discussion
of sexual issues within consultations did not appear to be influenced by the presence of a
male practitioner. In the 17 consultations where sexual issues were raised, the HCP was male on 11 / 17 (64.7%) occasions.

Sexual issues were discussed in consultations regardless of whether or not the woman had a current partner, with 12 / 17 (70.5%) women in a current relationship compared to five out of 17 (29.4%) of women without a current partner. The proportion of women with or without a current partner in this sub-group of consultations was comparable to those in the overall sample of observed consultations (n = 69) with 48 / 62 (77.4%) women in a current relationship, 14 / 62 (22.6%) not in a current relationship and seven out of 69 (10.1%) missing data where the relationship status of the woman was unknown.

The presence of someone accompanying the woman at her consultation (n = 30 / 43.5%), usually her partner, an adult child or a friend, did not appear to influence the topics discussed and accompanying individuals rarely contributed to consultation discussions directly.

Eleven out of 50 (22%) women with a gynaecological cancer diagnosis were asked about their sexual function compared to six out of 19 (31.5%) women with a non-gynaecological diagnosis. In considering the influence of relevant illness and treatment related factors on the discussion of sexual issues it was interesting to note that sexual issues were just as likely to be raised in consultations where the woman's primary diagnosis was that of anal or rectal cancer. The slightly raised profile of sexual issues discussion among women with anal and rectal cancer may have been influenced by the fact that all six of these women were entered in clinical trials where specific vaginal toxicity and sexual morbidity data sheets were completed at each out-patient consultation. None of the women with a gynaecological cancer diagnosis took part in clinical trials during this study.

Another factor that was believed by health professionals to influence the priority of topics discussed in consultations was the time elapsed since completion of the woman's treatment. It would be reasonable to assume that both patient and health professional concerns may alter and some may even diminish as time post-treatment increases, assuming there had not been disease progression or recurrence. The 69 consultations were grouped into three key time points post-treatment, with 31 (44.9%) women under six months post-treatment, nine (13%) at six to 11 months post-treatment and 29 (42%) who had completed treatment 12 months or longer.
As can be seen in table 5.3, consultations where sexual issues were raised were fairly evenly spread across each of the time periods in question.

Table 5.3: Discussion of sexual issues in relation to time elapsed post-radiotherapy completion

<table>
<thead>
<tr>
<th>Summary of time post treatment into &lt; 6 months, months</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Women &gt;/= 12months post pelvic RT</td>
</tr>
<tr>
<td>Summary of any sexual issues present / absent in consultation</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>29</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 2.371, \text{ df} = 2, p = 0.306 \] Pearson Chi-Square (2-sided)

Another factor considered influential regarding whether or not sexual issues were raised in a consultation was how many other clinical problems or issues were considered important to discuss from both the health professional and women’s perspective. As consultations are notoriously time-limited exchanges, the question considered for analysis was the extent to which the overall number of topics discussed in a consultation influenced whether or not time was made to also raise more sensitive discussion topics such as the woman’s sexual well-being. Again, in order to explore the relationship between these consultation attributes or variables a 2 x 2 contingency table was subjected to statistical analysis using Pearson’s Chi-Square test.

Data were grouped into consultations with a high number of topic content (6-10 topics per consultation) and those with a low number of topics (two to five topics per consultation). There were no consultations with a topic count less than two or greater than 10, although the duration of consultations ranged from 15 to over 30 minutes and was influenced not only by the number of topics discussed but also the nature of content in terms of its complexity, significance and emotional impact for the woman in question. As can be seen from Table 5.4, the result was not statistically significant, with sexual issues equally likely to occur in consultations where the topic count was high as it was to occur in those where fewer topics were discussed.
Table 5.4: Overall Topic Count for Consultations where Sexual Issues were raised

<table>
<thead>
<tr>
<th>Summary of any sexual issues present / absent in consultation</th>
<th>6 - 10 topics per consultation</th>
<th>2 - 5 topics per consultation</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>7</td>
<td>10</td>
<td>17</td>
</tr>
<tr>
<td>No</td>
<td>27</td>
<td>25</td>
<td>52</td>
</tr>
<tr>
<td>Total</td>
<td>34</td>
<td>35</td>
<td>69</td>
</tr>
</tbody>
</table>

\[ \chi^2 = .592, \text{ df} = 1, p = 0.442, \text{ Fisher's Exact test (1-sided)} p = 0.313 \]

One further aspect of consultation content which did not appear to influence the prevalence of sexual topics discussed in the consultation was the extent to which that consultation contained other psychological or social topics as a potential context for the discussion of sexual well-being. Psychological or social topics occurred in 29 (42%) of consultations.

Table 5.5: Consultations where both psychosocial and sexual issues were raised

<table>
<thead>
<tr>
<th>Summary of any sexual issues present / absent in consultation</th>
<th>Summary of psychosocial issues issues present / absent in consultation</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>No</td>
<td>22</td>
<td>30</td>
</tr>
<tr>
<td>Total</td>
<td>29</td>
<td>40</td>
</tr>
</tbody>
</table>

\[ \chi^2 = .007, \text{ df} = 1, p = 0.935, \text{ Fisher's Exact test (1-sided)} p = 0.582 \]

As can be seen from Table 5.5, there was no difference in the prevalence of sexual issues content in consultations in relation to the presence or absence of psychosocial discussion.
In interpreting this result it is important to note that an inclusive definition of psychosocial content was adopted, incorporating both brief enquiries such as ascertaining a woman's occupation to more detailed discussions such as the nature of family support in the presence of progressive illness.

In tables 5.2 to 5.5, and from the findings presented thus far, there were a number of factors that did not appear to have any influence on the prevalence of sexual issues as a consultation discussion topic. In contrast, there were six factors identified from the data (see Table 5.6) that appeared to act either as triggers or barriers to the discussion of sexual concerns between health professionals and women.

**Table 5.6: Potential Barriers and Triggers for the Discussion of Sexual Issues**

<table>
<thead>
<tr>
<th>Potential Barriers</th>
<th>Trigger Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women's Age &gt; 60 years</td>
<td>Clinical Trial Toxicity Data Monitoring</td>
</tr>
<tr>
<td>Late clinical disease stage (III / IV, T3/T4)</td>
<td>Presence of Vaginal Toxicity</td>
</tr>
<tr>
<td>Disease Relapse / Progression</td>
<td>Discussion of Dilator Provision / Use</td>
</tr>
</tbody>
</table>

5.3.1 Perceived barriers to discussion of sexual issues in observed consultations

**Women's Age**

Women who took part in this element of the study varied in age from 31 - 40 years of age (n = 4 / 5.8%) to >80 years of age (n = 2 / 2.9%) with the majority of women (n = 21 / 30.4%) falling into the 61 - 70 years age group. As the data were distributed across six age-groups it was collapsed into two overarching categories (women ≤ 60 years and women over 60 years of age) for the purpose of analysis.

Pearson's Chi-Square was used to determine whether or not older women (over 60 years of age) were less likely to have discussions about sexual issues than younger women (under or equal to 60 years of age).

As can be seen from Table 5.7, there was a statistically significant difference (at the one per cent level) between the two age categories of women, with older women less likely to have discussions about sexual issues than those aged 60 years or younger.
Table 5.7: Influence of Women's Age on the Discussion of Sexual Issues

<table>
<thead>
<tr>
<th>Summary of patient age groups into younger/older than 60 years of age</th>
<th>Summary of any sexual issues present / absent in consultation</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under or equal to 60 years of age</td>
<td>Yes</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>17</td>
</tr>
<tr>
<td>Over 60 years of age</td>
<td>No</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td></td>
<td>33</td>
</tr>
<tr>
<td></td>
<td></td>
<td>52</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>32</td>
</tr>
<tr>
<td></td>
<td></td>
<td>37</td>
</tr>
<tr>
<td></td>
<td></td>
<td>69</td>
</tr>
</tbody>
</table>

* $\chi^2 = 8.215$, df = 1, $p = 0.004$, Fisher's Exact test (1-sided) $p = 0.005$

Clinical Stage of Illness and Disease Relapse or Progression

Two overlapping illness related factors that appeared to reduce the likelihood that sexual issues would be discussed as a late effect of treatment were that of late clinical stage (stage III/IV, T3/T4) and the presence of disease relapse or progression. Women with more advanced stages of cancer were likely to have a greater number of illness or treatment related symptoms that could impact their overall quality of life and sense of well-being. These symptoms would usually require a health professional response in terms of further diagnostic investigations or active symptom management. Furthermore, the presence of progressive illness could also lead to a re-prioritisation of life issues, which for some women or couples may reduce the perceived importance or relevance of sexual well-being in relation to the woman's prognosis. Disease prognosis and "bad news" discussions were present in 15% of observed consultations and 38 / 67 women (56.7%) had later stage disease, 12 (17.4%) of whom also had progressive or relapsed disease at consultation. Clinical stage data were missing for two of the women and they were excluded from this analysis. Table 5.8 suggests that women with late stage disease were less likely to have discussion of sexual issues in their consultations than women with earlier stage cancer ($p = 0.039$). This is a statistically significant difference at the five percent level.
Table 5.8: Influence of Clinical Disease Stage on the Discussion of Sexual Issues

<table>
<thead>
<tr>
<th>Summary of patient's clinical disease stage into early (1/2) &amp; late (3/4) stage</th>
<th>Early Stage disease (I, II, T1, T2)</th>
<th>Late Stage Disease (III, IV, T3, T4)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary of any sexual issues present / absent in consultation</td>
<td>Yes</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>18</td>
<td>32</td>
</tr>
<tr>
<td>Total</td>
<td>29</td>
<td>38</td>
<td>67</td>
</tr>
</tbody>
</table>

*χ² = 4.258, df = 1, p = 0.039, Fisher’s Exact test (1-sided) p = 0.038*

The factors that acted as a barrier to the discussion of treatment-related sexual concerns in the follow-up clinic were also present in participant’s interview data and are discussed in detail within chapter nine: “Talking Sex” in the clinic.

### 5.3.2 Perceived triggers to discussion of sexual issues in observed consultations

**Clinical Trial Toxicity Data Monitoring**

As you will recall from Figure 5.1, only bowel toxicity (81%), bladder toxicity (70%) and enquiries about pain (61%) were treatment effects routinely recorded in the majority of clinical consultations observed. This suggests that formal strategies or methodologies for the routine clinical assessment of radiotherapy toxicities (acute or late) were not in use in the research sites where participant observation took place. However, at research site A, six out of 19 (31.5%) women were enrolled in two clinical trials investigating the use of chemo-radiotherapy in the management of anal and rectal carcinoma. Both of these trials required completion of detailed treatment morbidity assessment sheets based on the RTOG (Radiation Therapy Oncology Group) scoring system for acute radiation reactions, the CTC version 2 (Common Toxicity Criteria) for combined chemotherapy and radiotherapy side effects and the LENTSOMA (Late Effect on Normal Tissue, Subjective, Objective, Management, Analytic) assessment system for recording radiotherapy late toxicities. The LENTSOMA scales are most relevant in relation to recording the late effects of pelvic radiotherapy on female sexual function. Medical staff or research nurses were expected to complete toxicity sheets during the consultation that comprised a total of 13...
elements including *Female Sexual Dysfunction, Vaginal Toxicity* and *Vulval Toxicity*. Scrutiny of the content of these toxicity score sheets revealed that health care professionals were prompted to ask for relatively detailed information including:

<table>
<thead>
<tr>
<th>Sexual Morbidity Items</th>
<th>Vaginal / Vulval Toxicity Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual Desire</td>
<td>Vaginal Stenosis</td>
</tr>
<tr>
<td>Frequency of Intercourse</td>
<td>Vaginal Length</td>
</tr>
<tr>
<td>Dyspareunia</td>
<td>Vaginal Ulceration</td>
</tr>
<tr>
<td>Orgasm</td>
<td>Vaginal Dryness</td>
</tr>
<tr>
<td>Sexual Satisfaction</td>
<td>Tissue Atrophy</td>
</tr>
<tr>
<td></td>
<td>Vulval pruritis</td>
</tr>
</tbody>
</table>

While emphasis was predominantly placed on assessment of physical signs of vaginal or vulval tissue toxicity, within the scoring system for female sexual dysfunction the health care professional was prompted to enquire about vaginal dilation, use of intimate lubricants and hormone replacement therapy.

Although the sample size of women involved in clinical trials was low, Pearson's Chi-Square was used to test whether or not there was a statistically significant relationship between the use of trial toxicity sheets and the discussion of sexual issues within consultations. The results of this cross-tabulation demonstrated a statistically significant relationship at the one per cent level between participation in a clinical trial and the discussion of sexual issues within these women's consultations (see Table 5.9).

**Table 5.9: Influence of Pelvic Radiotherapy Trial Toxicity Data Monitoring on the Discussion of Sexual Issues**

<table>
<thead>
<tr>
<th></th>
<th>Patient Included in Trial Toxicity Data</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Summary of any</strong></td>
<td><strong>Yes</strong></td>
<td><strong>No</strong></td>
</tr>
<tr>
<td>sexual issues</td>
<td>11</td>
<td>52</td>
</tr>
<tr>
<td>present / absent</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>in consultation</td>
<td>17</td>
<td>52</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>69</td>
<td></td>
</tr>
</tbody>
</table>

\[ \chi^2 = 20.101, \text{df} = 1, p = 0.000, \text{Fisher's Exact test (1-sided)} p = 0.000 \]
Presence of Vaginal Toxicity
As discussed earlier in this chapter, symptoms of vaginal toxicity associated with pelvic radiotherapy were elicited in 29 (42%) consultations. I was interested to ascertain whether or not the presence of vaginal symptoms would lead practitioners to then enquire about the woman's adherence to commonly recommended prophylactic interventions (vaginal dilator use, lubricant use) or to explore the impact of such symptoms, if any, on the woman's sexual well-being. Having already demonstrated a statistically significant relationship between vaginal toxicity and discussion of the provision and use of vaginal dilators (Table 5.1) Pearson's Chi-Square was again used to explore whether or not there was a statistically significant relationship between the presence of vaginal toxicity, and the discussion of sexual issues with women.

Table 5.10 illustrates this relationship in a 2 x 2 contingency table, demonstrating a statistically significant difference at the one per cent level between the two groups.

<table>
<thead>
<tr>
<th>Summary of any vaginal toxicity symptom present / absent in consultation</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary of any sexual issues present / absent in consultation</td>
<td>Yes</td>
<td>17</td>
<td>0</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
<td>40</td>
<td>52</td>
</tr>
<tr>
<td>Total</td>
<td>29</td>
<td>40</td>
<td>69</td>
</tr>
</tbody>
</table>

*χ² = 31.114, df = 1, p = 0.000, Fisher's Exact test (1-sided) p = 0.000

In the 17 consultations where sexual issues were discussed, vaginal toxicity was also raised in each case, compared to 40 consultations where no vaginal toxicity was discussed and sexual issues were not raised on any occasion. There were 12 consultations where vaginal toxicity was raised but sexual issues were not discussed. Scrutiny of the specific characteristics of these women indicates that the majority (9 / 12) were older than 60 years of age and 11 / 12 had a primary gynaecological diagnosis. There did not appear to be any relationship between the absence of sexual issues as a discussion topic and stage of disease, time elapsed post-treatment or whether the woman
had a current partner. The most common symptom was vaginal bleeding \((n = 6)\) with vaginal stenosis or shortening reported in three consultations, vulvo-vaginal pruritis in two and vaginal discharge in one consultation. It is interesting to speculate about the impact these vaginal symptoms may have had on the woman’s sexual relationship, but which remained unexplored in this consultation context.

**Table 5.11: Relationship between discussion of vaginal toxicity, dilator use and sexual issues in observed consultations**

<table>
<thead>
<tr>
<th>Primary Diagnosis (Observation/Case)</th>
<th>Clinical Stage</th>
<th>Clinical Trial</th>
<th>Age (yrs)</th>
<th>Vaginal Toxicity N=19/29</th>
<th>Dilator Use N=16</th>
<th>Sexual Issues N=17</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anus (Anorectal 8.3)</td>
<td>T2</td>
<td>✓</td>
<td>41-50</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Anus (Anorectal 8.5)</td>
<td>T1</td>
<td>✓</td>
<td>51-60</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Rectum (Anorectal 17.1)</td>
<td>T3</td>
<td>✓</td>
<td>41-50</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Rectum (Anorectal 21.2)</td>
<td>T3</td>
<td>✓</td>
<td>51-60</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Rectum (Anorectal 22.1)</td>
<td>T3</td>
<td>✓</td>
<td>61-70</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Anus (Anorectal 22.2)</td>
<td>T2</td>
<td>✓</td>
<td>51-60</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Cervix (Gynaecological 9&amp;10.1)</td>
<td>II</td>
<td>X</td>
<td>51-60</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Endometrium (Gynaecological 9&amp;10.5)</td>
<td>I</td>
<td>X</td>
<td>61-70</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Endometrium (Gynaecological 11.1)</td>
<td>II</td>
<td>X</td>
<td>51-60</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Endometrium (Gynaecological 12.4)</td>
<td>II</td>
<td>X</td>
<td>51-60</td>
<td>✓</td>
<td>X</td>
<td>✓</td>
</tr>
<tr>
<td>Cervix (Gynaecological 12.5)</td>
<td>I</td>
<td>X</td>
<td>41-50</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Endometrium (Gynaecological 19.2)</td>
<td>II</td>
<td>X</td>
<td>41-50</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Cervix (Gynaecological 20.2)</td>
<td>III</td>
<td>X</td>
<td>41-50</td>
<td>✓</td>
<td>X</td>
<td>✓</td>
</tr>
<tr>
<td>Endometrium (Gynaecological 23.2)</td>
<td>II</td>
<td>X</td>
<td>61-70</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Endometrium (Gynaecological 23.3)</td>
<td>II</td>
<td>X</td>
<td>71-80</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
</tr>
<tr>
<td>Cervix (Gynaecological 24.1)</td>
<td>I</td>
<td>X</td>
<td>41-50</td>
<td>✓</td>
<td>X</td>
<td>✓</td>
</tr>
<tr>
<td>Endometrium (Gynaecological 24.4)</td>
<td>II</td>
<td>X</td>
<td>71-80</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
</tr>
<tr>
<td>Endometrium (Gynaecological 29.3)</td>
<td>II</td>
<td>X</td>
<td>71-80</td>
<td>✓</td>
<td>X</td>
<td>✓</td>
</tr>
<tr>
<td>Endometrium (Gynaecological 30.2)</td>
<td>III</td>
<td>X</td>
<td>51-60</td>
<td>✓</td>
<td>X</td>
<td>✓</td>
</tr>
<tr>
<td>Endometrium (Gynaecological 30.4)</td>
<td>III</td>
<td>X</td>
<td>61-70</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

**Key:** ✓ = Yes / Topic discussed in consultation  
X = No / Topic NOT discussed in consultation
Discussion of Dilator Provision / Use

As there was considerable overlap (15 / 29; 51.7%) between discussion of the consultation content topics of dilator provision / use (n = 15) and vaginal toxicity (n = 29, see Table 5.1) it follows that the relationship between the discussion of vaginal dilator provision / use and discussion of sexual issues is also statistically significant at the one per cent level ($\chi^2 = 35.995$, df = 1, p = 0.000, Fisher’s Exact test (1-sided) p = 0.000).

Table 5.11 provides a summary of the relationship between the three consultation topics of vaginal toxicity, vaginal dilator provision and discussion of sexual issues.

It is interesting to note that in the three consultations where vaginal toxicity and / or vaginal dilator use are discussed, yet sexual issues are omitted, all women had early stage disease, had a current partner, but all were older women in the 71-80 age group.

5.4 Discussion of Participant Observation Findings

The participant observation findings discussed in this section are those considered to be key contributors to development of an understanding of this study’s research questions and are also most relevant to the subsequent analysis and interpretation of the qualitative interview data presented in chapters six to ten. Where possible triangulation of data was used to demonstrate where corroboration of findings occurred between the naturally occurring data from participant observation of follow-up clinics, and findings emanating from participants’ interviews.

Direct comparisons between the findings of studies that specifically investigate the sexual sequelae of pelvic cancer treatment and the prevalence of enquiries about sexual function within naturally occurring data from routine medical follow-up clinics may inevitably lead to an overly negative critique of current clinical practice. However, as health care professionals commonly rely on findings from biomedical literature to inform their practice it is appropriate to explore how female sexuality is framed within the realities of both clinical practice and clinical research. What emerges is that information about women’s sexuality generated through research is shaped by the dominant research paradigm (positivism) and study methodologies adopted, the dominant theoretical perspectives explored and the way in which questions about sexuality, sexual well-being or more commonly sexual function are framed within the study in question.

In comparing findings from participant observation in this ethnographic study with those from the published literature, only two studies were identified from the literature
review (Weijts et al. 1993; Meerabeau, 1999) that had also used naturally occurring data to explore whether and how sexuality was discussed in clinical settings. Weijts et al (1993) taped 32 consultations between 15 women (aged 18-49 years) and five male gynaecologists, subjecting the transcripts to conversation analysis, while Meerabeau (1999) conducted observation in fertility clinics. Although the overall frequency with which sexuality was raised as a topic in Weijts et al's (1993) study is not reported, his paper found that almost 50% of the women mentioned sexual issues after first talking about other gynaecological complaints with their doctor. This delay in addressing sexual issues was interpreted as reluctance on the part of women to discuss what was experienced as a sensitive topic with their gynaecologist. Meerabeau (1999) found that sexual issues were raised in a total of six out of 160 (3.7%) observed consultations, compared to a frequency of 17 / 69 (24.6%) in the gynaecological and colorectal follow-up clinic consultations observed in this study.

In comparing the frequency of sexual issues discussed within medical consultations it is important to note that in both of the published studies, the age group of women was pre-menopausal and thus a substantially younger patient sample than the women observed in this study. The influence of age on the likelihood that sexual issues are discussed in consultations is addressed in more detail within interview findings presented in chapters seven and nine.

Another factor that should be taken into account in making comparisons between studies is the influence of the medical speciality as a context for clinical discussions. Matocha and Waterhouse's (1993) survey suggested that while nurses considered the discussion of sexuality to be of moderate importance in oncology, this topic was rated as most important in gynaecology, mental and community health settings.

5.4.1 Content of Consultations between Health Care Professionals and Women receiving Pelvic Radiotherapy

The most common topics discussed during radiotherapy follow up consultations in this study are consistent with a published audit by Denton et al. (2000). Both bowel and urological (bladder) toxicities were assessed during the majority of consultations (present in 81% and 70% of consultations respectively) compared to only 42% of consultations where vaginal toxicity was raised. Consistent with published oncology literature (Davidson et al. 2002; Davidson et al. 2003a; Saunders 2003) formal assessment methodologies for radiotherapy toxicity and late effects were not in routine use at either research site. The
consultation agenda was largely dependent on the assessment priorities of the clinician conducting the review together with the woman's disclosure of active problems. As can be seen from figure 5.1 the majority of consultation topics were usually physical treatment, illness related effects or discussions about future treatment and follow up plans. Despite the rhetoric of patient partnership and involvement in clinical decision making within healthcare and cancer policy (DH 1999, DH 2000, NICE 2004) the reality of clinical practice observed was that the agenda was set and led by health professionals with women's needs, perhaps understandably, largely framed within a biomedical gaze (Foucault, 1973; Hyde, 2007) that only infrequently took account of women's social contexts. 

Psychological and social topics were raised in a minority of consultations (42%), supporting recent findings from a survey of people living with cancer by Macmillan Cancer Support (2006) where although 45% of patients surveyed stated that the emotional effects of cancer were the most difficult ones to cope with (compared to 41% physical effects and 13% practical effects) 58% said they felt cancer services did not look after their emotional needs as well as their physical needs. In the Macmillan (2006) study, women (49% of women compared to 37% of men) and people from lower socio-economic groups (59% from lower socio-economic groups compared to 41% in higher socio-economic groups) found coping with the emotional effects of cancer most difficult.

5.4.2 Discussion of Vaginal Toxicity, Vaginal Dilator Use and Menopause Management in Women's Consultations with Health Care Professionals

The health care professionals and women in this study appeared to consider vaginal bleeding (spontaneous or post-coital) as a more noteworthy symptom (n = 17 / 24.6% of consultations) than the other types of vaginal toxicity reported in published studies (Bergmark et al. 1999; Jensen et al. 2003; Vistad, Fossa & Dahl, 2006; Brand et al. 2006). Schover et al. (1989) found that women who had received pelvic radiotherapy were more likely to report vaginal bleeding than women having surgical treatment alone. A small survey (n = 16) by Flay and Matthews (1995) and a qualitative study (n = 19) by Lamb and Sheldon (1994) explored the meaning women attributed to post-treatment vaginal bleeding. Some women felt "unclean" or "out of control" as a result of this symptom while others viewed it as a reminder of their disease or a sign that the cancer had returned, with 56% citing bleeding or fear of bleeding as a reason for reduced sexual activity with their partner (Lamb & Sheldon, 1994; Flay & Matthews, 1995). At no time in any of the
consultations I observed was a direct link made between the presence of vaginal bleeding, the actual or potential impact on the woman's sexual expression and the identification of any steps necessary to reduce or avoid this symptom.

As mentioned previously, the women and health professionals in this study did not discuss vaginal dryness, stenosis or shortening as frequently as the prevalence of these treatment effects in published studies of women treated by pelvic radiotherapy. Vaginal dryness was only raised in six (7.2%) consultations while published studies claim this is the most prevalent vaginal symptom that women experience (Vistad, Fossa & Dahl, 2006). Similarly, vaginal stenosis was discussed on 11 (15.9%) and vaginal shortening on nine (13%) occasions despite the widely varying stenosis prevalence rates in published literature ranging from 1.6 - 88% (Nori et al. 1994; Lancaster, 2004; Brand et al. 2006).

What is evident from the observation data and from published literature is that the prevalence of radiotherapy late effects such as vaginal stenosis are more likely to be reported in studies that specifically evaluate that symptom (Brand et al. 2006) as opposed to studies focusing on overall quality of life (QOL). The trend of finding what you specifically look for in research appeared to be echoed in clinical practice where women tended to restrict themselves to answering direct questions about vaginal symptoms from their treatment team as opposed to spontaneously raising these topics themselves. The issue of reluctance to discuss more intimate or sensitive topics on the part of both women and health professionals is discussed further in chapter nine: "Talking Sex" in the clinic.

Another finding from this study that is endorsed by research is the low priority given to evaluation of women's use of vaginal dilators within clinical oncology follow up (White & Faithfull, 2006). Discussions about the provision and use of vaginal dilators took place in only 16 (23.2%) consultations in this study. While radiotherapy department nurses and therapy radiographers were responsible for the supply of dilators and the provision of patient education to women, they were not involved in the women's post-treatment follow-up. Post-treatment follow-up was directed by medical staff at both research sites and it was uncommon for a nurse to be present in medical consultations other than to act as a chaperone for intimate (vaginal or rectal) examinations by male doctors or to oil the wheels of the clinic process. As found in White and Faithfull's (2006) survey of current dilator practice in the UK, there did not appear to be an agreed strategy for the evaluation of patient compliance with vaginal dilation as a prophylactic intervention, despite local policy that all women should receive these devices and be encouraged in their regular use. In the consultations observed, the discussion of vaginal dilators normally followed elicitation of
vaginal stenosis or vaginal shortening on examination or enquiry, resulting in a referral to the radiotherapy nursing service on seven out of 16 occasions. In the spirit of participant observation it was necessary for the researcher (also a cancer nurse) to prompt the discussion of vaginal dilators on a number of occasions where the doctor appeared uncertain regarding when and how these devices should be used. On such occasions I had to consider my professional and ethical responsibilities as a nurse researcher to ensure the woman came to no harm as a result of any observed practice omission. This intervention took precedence over my responsibility as a clinical researcher to minimise the impact of my presence on normal clinic process and colleague's practice. Through reflexivity I ensured I was aware of my influence on the nature of the observation data recorded and subsequently analysed.

The potential compounding effect of medically induced menopause symptoms on a woman's femininity and sexuality is discussed within the literature to varying degrees (Anderson et al. 1997; Juraskova et al. 2003; White & Faithfull, 2006). In the 69 consultations observed, 23 women (33.3%) were pre-menopausal at the time of their diagnosis and treatment. Of that group of women, only nine had any discussion of menopausal symptoms and their management resulting in one woman with cervical cancer being referred to the gynae-oncology clinical nurse specialist while another with anal cancer was referred to her GP for provision of hormone replacement therapy. This low level of routine enquiry about the management of medically induced menopause, together with limited use of a range of referral routes, may indicate the absence of an established referral pathway for the management of these difficulties within some follow-up clinics.

The only consistent referral pattern to emerge from analysis of observed consultations (site A only) related to the provision and use of vaginal dilators as a prophylactic intervention for the prevention of vaginal stenosis and shortening. In cases where stenotic changes or vaginal shortening had been elicited, or the woman had not received a set of vaginal dilators as intended, a referral was made to the radiotherapy department nursing service. This practice may suggest that the supply of instrumental or practical interventions is considered part of the women's rehabilitation service whereas the sexual and relationship dimensions of her illness experience appear to receive inconsistent or limited service provision. This resource limitation was apparent when, in my capacity as a researcher with psychosexual training, I was asked by a medical colleague if I would see five different women to explore specific sexual difficulties and to recommend onward referral following initial assessment. The relationship between a perceived lack of
specialist resources to address sexual difficulties and a reluctance to ask direct questions about women's sexual adjustment post-treatment is explored through analysis of interviews with health professionals in chapter nine. Perceived lack of resources and knowledge about sexual issues emanating from cancer treatment is one of the frequently cited reasons given by HCPs for not asking questions about sexuality from patients in their care (Gamel et al. 1993, Cort et al. 2001, Stead et al. 2001, Wilson and Williams 1988).

5.4.3 Discussion of Sexual Issues in Women's Consultations with Health Care Professionals

Arguably the presence of any reference to sexual issues in only 17 (24.6%) observed consultations may be considered low given the 50 - 80% prevalence rates of sexual difficulties following pelvic radiotherapy for gynaecological malignancy (Flay and Mathews 1995, Crowther et al. 1994, Jensen et al. 2003).

Outpatient consultations were experienced by women and health professionals as time-limited exchanges where sexuality as a topic had to compete with the perceived clinical priorities of side effect management and disease surveillance. Lack of clinical time to address psychological, social and sexual aspects of the patient's illness experience was often cited as a dominant reason for the low frequency of sexual health care within nursing and medical practice (Wilson and Williams 1988, Guthrie 1999, Gott et al. 2004, Stead et al. 2001). In this study, the clinics observed were busy in terms of volume of patients to be seen within the designated time set aside for that particular clinic. It was not uncommon for clinics to overrun and patients usually had to wait beyond their scheduled appointment time before being seen. Furthermore, some of the clinics were subject to multiple interruptions from medical or nursing personnel engaged in activities taking place in other parts of the hospital, but requiring the opinion or intervention of doctors in the clinic. As will be discussed further in chapters six, nine and ten, it may be argued that the follow-up clinic is not a suitable environment or context for the detailed discussion or assessment of female sexual difficulties after cancer treatment because of its time constraints, topic prioritisation and staff disruption resulting from the need to multi-task.

As can be seen in figure 5.3 there were a total of five overlapping domains of sexual expression explored to a limited degree within the consultations observed, the most common simply being an enquiry by the health professional (n = 11) or a comment from the patient (n = 6) as to whether or not the woman was currently sexually active. The
remaining sexual concerns were normally elicited through the use of probes dictated by
the woman's response to that initial overarching question.

Closer exploration of the sexual issues elicited from observation of oncology follow-
up clinics revealed a heterosexist and largely functionalist view of female sexuality, with
emphasis placed on the woman's interest in, frequency of and ability to engage in
penetrative vaginal intercourse. The discussion of female sexuality practised in these
outpatient clinics is congruent with the dominant biomedical perspective in published
oncology research (Hyde, 2007) but represents a more restricted portrait of female
sexuality than that found in contemporary biomedical literature. While early studies of
sexual morbidity predominantly relied upon frequency of sexual intercourse as a measure
of sexual adjustment and recovery post-treatment, those from the 1990s onwards were
more likely to investigate treatment impact on the key phases of the human sexual
response cycle (Masters and Johnson 1966) including evaluation of changes in level of
sexual desire (interest), physiological signs of sexual arousal (vaginal lubrication, absence
of dyspareunia) and the ability to achieve orgasm (Kylstra et al. 1999, Andersen et al.
1997, Hendren et al. 2005). The majority of contemporary studies also include some
exploration as to whether or not the woman's level of sexual satisfaction post-treatment
compares favourably with her pre-diagnosis sexual well-being (Pieterse et al. 2006,

In contrast to the literature there was no discussion of the woman's subjective
experience of sexual expression in observed consultations. No enquiry was made as to
whether or not the women experienced sexual satisfaction or whether she had
experienced changes to her orgasmic capacity post-treatment. The focus of clinic
discussions remained the woman alone; with no health professional enquiry regarding the
impact altered sexuality may have had on the woman's sexual partner. In only two
consultations did women allude to concerns they had about reduced interest in and
frequency of sexual intercourse and the regrets they had in relation to their partner's
sexual enjoyment. This lack of focus on the couple relationship encountered in clinical
consultations is mirrored within the biomedical literature with only a minority of
gynaecological studies (DeGroot et al. 2005, Van De Wiel et al. 1990, Van De Wiel et al.
1988) exploring the sexual impact of cancer therapy on the partner's sexual well-being or
on the relationship as a whole. These findings from participant observation are developed
in more detail within chapter seven: Constructions of Female Sexuality after Cancer
Treatment. The full nature and meaning of sexual changes experienced by women, yet not

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fully addressed within their follow-up management, are explored in interview findings within chapter eight: Living with a changed sexual life after cancer.

As identified in section 2.4 of the literature review, a number of factors are identified as either acting as barriers to talking about sexuality with patients or enabling such discussions to take place. These factors elicited from participant observation data are consistent with those discussed in interviews with women and health professionals and are presented in more detail within chapter nine: "Talking Sex" in the clinic.

Burd et al. (2006) found that health professionals were uncomfortable, and perceived their patients to be uncomfortable, in opposite gender consultations. As the total number of consultations conducted by female health professionals where sexuality was discussed was low (n = 4 / 23.5%), and participant observation did not permit exploration of participant's comfort and motivation regarding the topics discussed, it is not possible to state confidently whether or not the prevalence and depth of discussions about sexual issues was influenced by health professional gender for at least some of the women. This is a factor that is explored specifically within the interview data of this study and will enhance subsequent interpretation of observation data in this respect.

Burd et al. (2006) also found that doctors experienced greater "discomfort" in discussing sexual issues with patients who were aged over 60 years, did not have a current sexual partner and had lower education levels. The educational level of patients was not a factor explored in the present study and sexual issues appeared to be discussed regardless of whether or not the woman had a current partner, occurring in five consultations (n = 5/17, 29.4%) with single women.

However, the age of women did appear to influence health professional behaviour independently of other factors. As can be seen from table 5.7, sexual issues were more likely to be discussed with women who were younger than 60 years of age, regardless of their primary diagnosis or the time elapsed post-treatment. Further interpretation of this factor is again possible through analysis of the health care professional interview data in this study and it would appear that older women are regarded differently by health professionals in relation to the legitimacy of addressing sexual issues related to their illness or treatment. Gott et al.'s (2004a) study of GPs’ management of sexual health in later life also found a reluctance among doctors to discuss sexual matters with older people, recognising ageist assumptions about this client group being less likely to be
sexually active and fearing causing offence to those who may hold more traditional views about the legitimacy of sexual expression as a health care concern.

Another finding from Gott et al.'s (2004a) study that is also relevant to the interpretation of this data was that doctors frequently used the discussion of contraception or reproductive health as a vehicle for broaching the more sensitive topic of sexual well-being among their patients. When this option was removed, for example in speaking to post-menopausal women, sexual health issues were less likely to be addressed. This finding may explain the close relationship between discussion of vaginal toxicity, vaginal dilator use and the subsequent discussion of sexual issues in consultations within the present study. Doctors may find it more comfortable to use the elicitation and discussion of vaginal symptoms as a vehicle for enquiring about sexual recovery post-treatment as opposed to raising sexual health issues independently. However, the linkage of these two factors fails to adequately explain why sexual issues were not discussed in 12 / 29 (41.3%) consultations where vaginal toxicity had already been raised. The only factor that appeared to account for this apparent omission was that 75% (n = 9 / 12) of this subgroup of women were older than 60 years of age.

One factor that appeared particularly influential within oncology in determining whether or not sexual issues are discussed in the clinical setting relates to the clinical stage of the patient's illness and the woman's physical well-being. Women with stage I or II (early stage) disease were found to be more likely to have discussion of sexual concerns with their treatment team than women with late stage (clinical stage III or IV) disease, 11 / 29 (37.9%) women with early stage compared to six out of 38 (15.7%) women with late stage disease. As can be seen from table 5.8, the difference in these two groups was statistically significant (* $\chi^2 = 4.258$, df = 1, $p = 0.039$, Fisher's Exact test (1-sided) $p = 0.038$) at the five per cent level. Changed priorities associated with the experience of advanced cancer has the potential to influence patient, partner and health professional's motivation for and comfort in addressing sexual concerns (Hordern & Street, 2007a). A study from the field of disability and rehabilitation found that 54% of health professionals considered a patient's poor physical well-being as a barrier to discussions about sexual issues (Haboubi and Lincoln 2003).

5.4.4 Concluding Comments

Analysis of naturally occurring data from participant observation of oncology follow-up clinics provides an insight into the reality of medical and nursing practice in busy clinical

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environments. As will be discussed later in this thesis, women experienced a lower level of enquiry about their psychosocial and sexual well-being during follow-up than the attention paid to their physical recovery and disease surveillance. However, as will be seen in the interview findings presented in chapters six and nine, the majority of women who took part in this study would endorse this follow-up focus, as their overriding priority was to ensure their cancer had not progressed or recurred.

Interpretation of these findings in light of published literature has identified a number of themes that will be subsequently explored both independently and through triangulation within the interview data in subsequent chapters of this ethnography.
Chapter 6: The Culture of the Clinic

6.1 Introduction

This data category encompasses the persistent characteristics of the oncology follow up clinic that demonstrate its purpose, related behaviours and functions. More specifically, data coded under this category represent elements of the clinic environment, the actors engaged in clinic activities (the business of the clinic) and the recurring roles and behaviours that contribute towards defining the clinic purpose for the women who attended the clinic, their partners and the staff responsible for its running.

Figure 6.1: Data categories and sub-categories: The Culture of the Clinic

Descriptions of the clinic environment are provided in section 3.6.3, “Entering the field and experiencing the clinic”. Details relating to the nature of the follow up clinics observed and the actors present in the clinic setting are found both in the participant observation data (chapters four & five) and within the interview findings presented in this chapter.
There was consistency across health professional participants and some patient participants between the observation and interview elements of this study. However, while observation of clinics took place at both research sites A and B, patient and partner interview participants were recruited solely from site A.

During the initial stages of the data analysis process, 11 data categories were identified from the interview transcripts of study participants that captured their experience of participating in oncology follow-up clinics at these cancer centres. Figure 6.1 identifies the initial categories and sub-categories identified, together with the final six data categories generated following the processes of qualitative data analysis. Details of the data analysis approach used in this study are presented in section 3.7.

6.2 Information Priorities

Information priorities can be defined as the clinical information identified by health professionals, patients and their partners as important in promoting understanding of the women's illnesses, treatment(s) and associated side effect management. This information was considered not only an important component of patient education but also constituted aspects of post-treatment clinical assessment where the same information topics, particularly those associated with treatment toxicity, were the focus for evaluating patient side effects and symptoms following treatment completion.

Verbal and written information was provided and discussed by a range of health professionals at two key points in the patient's care trajectory:

- Before treatment as part of informed consent
- During radiotherapy treatment as part of the on-treatment review process

Patient information delivery during follow up was characterised by verbal information given in response to active patient symptoms or problems elicited during consultations.

During the process of obtaining informed consent, prior to commencement of radiotherapy, the information exchange was initiated and directed by medical staff with nurses and women's partners sometimes present during this discussion. Information delivered through on-treatment review clinics was by radiotherapy department nurses in research site A and therapy radiographers in research site B while follow up clinic consultations were led by medical staff. Patients, partners and health professionals engaged in follow up care after pelvic radiotherapy were asked about the information given in relation to both the acute and delayed effects of pelvic radiotherapy as can be seen from
the interview schedules in appendices 15-17. Women who had received pelvic radiotherapy and their partners were asked to recall what pelvic radiotherapy symptoms / side effects health professionals had told them to expect either during or after their radiotherapy treatment period. They were also asked what they remembered being asked about during medical follow up clinics.

Health professionals were asked what they considered were the priority elements in their assessment of the acute and late effects associated with pelvic radiotherapy and at what points in the cancer patient journey such assessments took place. The aim was to establish the extent to which information about and assessment of sexual morbidity associated with pelvic radiotherapy was an element of routine clinical assessment and practice through asking what information and assessment topics dominated patient and health professional consultations.

Discussions that took place at the point of obtaining consent for pelvic radiotherapy treatment was guided by clinician priorities and the focus of structured consent forms in use at research site A and by clinician priorities alone in research site B. Topics covered in these discussions were principally the rationale for radiotherapy treatment, details of radiotherapy delivery techniques and the acute and delayed side effects of pelvic irradiation or chemo-radiation. The majority of health professionals acknowledged that greater detail and emphasis was accorded to discussion of acute radiation toxicities likely to be experienced by patients such as skin irritation, bowel and bladder side effects and fatigue.

"...I suppose it's right to say that following pelvic radiotherapy there's acute and long term side effects which you deal with slightly differently...I suppose you would probably be more thorough regarding acute side effects..."

[HCP03: Male clinical research fellow]

In relation to the late effects of treatment, health professionals addressed medically induced infertility and menopause among pre-menopausal women, with some practitioners including information about hormone replacement therapy where appropriate.

Vaginal side effects that were discussed included vaginal dryness, vaginal bleeding (linked to mention of telangectasia), the development of vaginal adhesions, fibrosis and stenotic changes, vaginal shortening and the potential development of vesico-vaginal / recto-vaginal fistulae as a more rare but serious late effect of treatment.

As discussed later in this chapter, the majority of health professionals tended to discuss the late effects of treatment that were manifest in the vagina in conjunction with
information regarding the rationale for vaginal douche and dilator use. Despite the close relationship between vaginal changes and their potential impact on sexual expression and well-being, many health professionals acknowledged that they did not always identify the specific sexual implications of such changes at the time of treatment consent due to the burden of information and perceived high levels of patient anxiety normally associated with the diagnosis and start of treatment.

"Because they’re worrying so much about the cancer and that’s their priority. And also they’re not feeling like having sex when they’ve just been told they’ve got cancer and so it’s right down the bottom of their priority list. When they’re alive in 5 years time then it’s more important!" [HCP01: Female specialist registrar]

However, a minority of health care professionals addressed the possibility of the development of sexual difficulties such as loss of sexual desire, dyspareunia, or made brief reference to the maintenance or resumption of sexual intercourse following radiotherapy.

When women were asked to recall information given to them prior to treatment commencement there was considerable variation in the level of detail recalled that did not appear to be solely related to the length of time elapsed since their treatment completed. Acute bowel toxicity (diarrhoea) was the most commonly recalled information about treatment side effects together with skin irritation, bladder toxicity, fistula formation, fatigue and menopause. The majority of women did not spontaneously recall information given to them about vaginal changes, while a minority mentioned vaginal side effects such as irritation, shortening, shrinkage or pain and other difficulties associated with intercourse together with the “feminine care instructions” (regarding vaginal douche and dilator use) given to them by health professionals to minimise such effects (see section 7.4). However, there was a sense that the discussion of vaginal changes did not receive the same profile as mention of bowel and bladder effects.

"I think you need to know in advance what is being done to your body. .....how this will affect you, not just physically with, you know, not just with your bowel, not just with your bladder, but how this will also, the third thing down there is your sex organs, it’s your genitals. How this will affect our genitals as well and that’s equally important as the other two..." [PT03: 55 yr old woman, 8 months post surgery / radiotherapy for endometrial cancer]

Information recalled by the small number of male partners (n=5) that took part in the study tended to concur with the information given to patients at the time of consent,
although two of the five male partners requested specific information about the sexual consequences of pelvic radiotherapy so they could anticipate the likely impact on the couple’s sexual life.

“PTNR02: Well, I'll be honest, one of the first questions...I think whether it was even in the first interview, ehm, certainly one of the questions I asked, you know, what's it going to do to our sex life?
Researcher: And what kind of answer did you get, do you remember? I don't remember but I don't think, I mean it was, it certainly wasn't discouraging.”

[PTNR02: > 60 yr old gentleman married to PT10, a 68 yr old woman, 24 months post radiotherapy / anterior resection for rectal cancer]

From participant observation of the nursing clinics (section 5.1) and interviews with radiotherapy nurses (HCP07, 11 and 15) and therapy radiographers (HCP16 and 17) the content of women's review consultations during radiotherapy treatment, focused on the identification of acute skin, bowel or bladder side effects together with an introduction to the rationale for vaginal douche, dilator and intimate lubricant use as part of feminine care regimens to minimise vaginal late effects such as dryness, stenosis and shortening.

6.2.1 Information Priorities during Follow-Up Consultations

From both participant observation data and health professional interview accounts, the doctor's agenda for follow up consultations tended to focus on 3 key elements:

- Symptoms / signs of recurrent disease
- Disease response to treatment
- Treatment toxicity evaluation

Medical staff, women and partners agreed that the first priority during the follow up phase was that of detecting recurrence and that until the absence of recurrence was confirmed it was often difficult for women to focus on anything else in the consultation. Fear of Disease Recurrence (section 6.5) was such an important factor determining the women and health professional's experience of the clinic that it is addressed later in this chapter as a specific data category.

Medical staff also assessed the response of the woman's site of disease to the radiotherapy / chemo-radiotherapy delivered and this was then discussed with the woman and any partner present during the consultation. Treatment side effects and any active symptoms the woman was experiencing would also be a routine aspect of the follow up consultation, with a particular focus on bowel, bladder and, in the case of gynaecological clinics, vaginal toxicity associated with pelvic irradiation as elicited through vaginal
examination (VE). In the colorectal clinics, vaginal examination was only performed if the woman complained of active symptoms arising from that site.

While early (first three months) follow up consultations tended to focus on the resolution of acute treatment side effects, persistent symptoms that indicated treatment late effects did become a more consistent focus of discussion as the time post-treatment extended:

"So acutely, so if I was seeing them early on acute side effects, so diarrhoea, tiredness, appetite, nausea and skin problems, and bladder, acutely....and then seeing them later again bowels, change in bowel habit following radiotherapy, change in bladder symptoms as well, more frequency, that sort of thing you'd be looking for and then, depending on their age, hormonal symptoms."

[HCP01: Female specialist registrar]

Nursing staff and therapy radiographers also enquired about treatment side effects and their management although they did not evaluate treatment efficacy or disease recurrence. These professionals were more likely to enquire about the patient's emotional adjustment to diagnosis and treatment, body image concerns and to ask about the practical aspects of the treatment experience such as the availability of support, family issues or financial concerns.

Women focused on understanding the meaning of active symptoms and sought clarification about what to expect and what to consider "normal" patterns of recovery and resolution following pelvic radiotherapy:

"...I actually think putting people in touch with other people who've had the same sort of treatment is quite, would be quite a good thing if people were prepared to talk, because I think you don't know what's normal? [Researcher: Yeh, of course you don't.] That's what I find the difficult thing to do, what is normal? What are the bounds of normality? What, should you expect? You know I don't necessarily want to be looking out for these things but where is the norm, you know, what are the parameters of normal?" [PT21: 54 yr old woman, 18 months post chemo-radiotherapy for cervical cancer]

6.2.2 Vaginal, Reproductive and Sexual Consequences of Pelvic Radiotherapy

The discussion of vaginal changes associated with pelvic radiotherapy was included in routine follow up assessment in gynaecology clinics and normally associated with vaginal examination to exclude disease persistence or recurrence. In contrast, evaluation of vaginal toxicity did not routinely occur in the colorectal follow up clinics where women with rectal and anal tumours were reviewed. If women were taking part in a clinical trial then toxicity data sheets structured the consultation to the extent that questions were asked
regarding vaginal and vulval toxicity together with female sexual difficulties such as loss of sexual desire or dyspareunia.

"...Because I am particularly in GI I suppose gastro-intestinal side effects would, would be more prominent in my mind. Ehm and for non-trial patients, trial patients I suppose, you know, you are fully rigorous with the follow-up because you have to be."

[HCP03: Male clinical research fellow]

Vaginal examination only took place in colorectal clinics if the woman complained of a specific vaginal symptom such as discharge, bleeding or stenosis. This difference in routine practice raises questions as to whether vaginal examination was seen by medical staff predominantly as a method of disease detection (as in the gynaecological clinics) as opposed to a method for the clinical evaluation of vaginal toxicity.

"Researcher: And would a vaginal examination be a routine aspect or would it only be if the woman was complaining of specific symptoms?
HCP20: Depends very much on the site of the tumour. If there was any question of encroachment on the vagina I would always do a vaginal examination. If there wasn't, only if symptoms prompted it."

[HCP20: Female consultant clinical oncologist]

Table 6.1 provides a summary of the vaginal, reproductive and sexual morbidity issues discussed within routine follow up clinics. Analysis of the interview transcripts revealed a difference between the topics routinely addressed by medical staff versus those raised by nursing and radiography staff. The topics placed in bold in Table 6.1 are those that were solely raised by nursing or radiography staff while those in standard font were topics raised by all staff disciplines.

Medical staff tended to focus predominantly on direct physical changes affecting the vagina and ovaries together with their biomedical management, with only a minority of clinicians (four out of eleven medical participants) specifically addressing any aspect of sexual morbidity post-treatment.

"I mean I talk about vaginal dryness, that's almost invariable, and then I talk about adhesions and telangiectasia, I always talk about those, and ehm basically, the reason I talk about them is to highlight that actually you can do something about them. So I use it to prime patients as to why we recommend douches, why we recommend dilators. So those are the main areas I focus on, ehm."

[HCP05: Male specialist registrar]
Table 6.1: Vaginal, Reproductive and Sexual Consequences of Pelvic Radiotherapy discussed within follow up clinics

<table>
<thead>
<tr>
<th>Vaginal Changes</th>
<th>Reproductive Consequences</th>
<th>Sexual Consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaginal Cleansing &amp; Douche Use</td>
<td>Infertility</td>
<td>Presence / Absence of a Partner</td>
</tr>
<tr>
<td>Vaginal Discharge</td>
<td>Menopause</td>
<td>Partner Concerns re Sexuality</td>
</tr>
<tr>
<td>Vaginal Dilator Use</td>
<td>Hormone Replacement</td>
<td>Pre-Treatment Sexual Activity</td>
</tr>
<tr>
<td>Fear of Dilator Use</td>
<td></td>
<td>Resumption of Sexual Intercourse</td>
</tr>
<tr>
<td>Vaginal Dryness</td>
<td></td>
<td>Sexual Myths &amp; Cancer or RT</td>
</tr>
<tr>
<td>Vaginal Adhesions, Fibrosis &amp; Stenosis</td>
<td></td>
<td>Loss of Sexual Desire</td>
</tr>
<tr>
<td>Vaginal Shortening</td>
<td></td>
<td>Sexual Arousal Problems &amp; Use of Intimate Lubricants</td>
</tr>
<tr>
<td>Telangectasia &amp; Vaginal Bleeding</td>
<td></td>
<td>Vibrator Use</td>
</tr>
<tr>
<td>Fear of Causing Vaginal Damage</td>
<td></td>
<td>Dyspareunia</td>
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<tr>
<td></td>
<td></td>
<td>Difficulties with Sexual Intercourse</td>
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<tr>
<td></td>
<td></td>
<td>Orgasmic Difficulties</td>
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<td></td>
<td></td>
<td>Resolution Phase Problems</td>
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<td></td>
<td></td>
<td>Femininity &amp; Body Image Concerns</td>
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<td></td>
<td></td>
<td>Adverse Impact on Couple Intimacy</td>
</tr>
</tbody>
</table>

The majority of nursing and radiography staff (seven out of nine participants) appeared to address a more diverse range of issues related to both physical changes in the vagina and the potential impact of these changes on sexual well-being and femininity together with some exploration of the fears and myths experienced by both the woman and her partner. However, only one clinical nurse specialist interviewed appeared to conduct a comprehensive review of women’s sexual fears and concerns:

“Radiotherapy, I would talk about, ehm I’d....think about their age and their menopausal status first of all....dry skin, lubrication. I try and think about in the sexual response cycle which would be desire, arousal, ehm climax and resolution. And there seems to be lots, lots of people that have arousal problems, lots of people that perhaps are a bit dry and need guidance around that. There’s a lot of, ehm, issues to do with climax capacity if they have had previous surgery but there’s also quite a lot of worry about, can their husband catch the cancer [from them], can they have sex? There’s lots of myths and misconceptions as well about, about those things, so I try to structure it in my mind about that. I don’t ask those questions but I try to structure it in my mind about that but also listen to what they’ve said because it will come out very different from the patient....”

[HCP04: Female clinical nurse specialist in gynae-oncology]

In contrast to this nurse, and as can be seen from table 6.1, there was a greater focus on the biomedical aspects of vaginal and reproductive changes induced by radiotherapy than on the emotional or sexual implications of physical changes.
This dominant biomedical focus in consultations is explored in more detail later in this chapter within the data category **Limits of the Biomedical Gaze** (section 6.4).

### 6.3 Information Gaps

Interview schedules asked women and their partners what information, if any, they had been given about the sexual consequences of pelvic radiotherapy by their health care team, particularly during the follow-up phase of their management. The follow-up phase was focused on more specifically because it is during this phase of the patient’s cancer experience that one might expect sexual concerns to become more relevant as women begin to anticipate a return to their pre-illness lifestyle and the manifestation of treatment late effects is more likely to occur. However, many women also mentioned information they recalled being given at the time of treatment consent and associated with vaginal dilator and douche (feminine care) provision during treatment.

Health care professionals were asked what information was given to women / couples regarding the nature of sexual changes or difficulties associated with the acute or late effects of pelvic radiotherapy and also what information would normally be offered to women should they require further information or support as a result of sexual concerns or difficulties related to their treatment (see appendices 15-17).

As mentioned in the findings related to information provision, topics that were excluded from discussions at the time of consent tended to be ones that were not present on the standardised consent form (site A) or were not considered appropriate to address at this stage of the treatment journey where it was acknowledged patient anxiety was high and the potential for information overload greatest.

"And maybe make more of a point of it in the consent forms because I think in the consent forms they talk about fertility and menopause but they don't talk about narrowing, so I think that probably does need to be addressed as a common side effect, so it should be on the list, shouldn't it? It's not there, yeh, so I think it's just got forgotten probably. I mean I remember thinking it was only gynae patients that had that problem [vaginal stenosis] until I did my exam [FRCR] and I was like Oh.....rectum and anus, yeh, I didn't realise before. I don't think it's that well known to be honest."

[HCP01: Female specialist registrar]
"I have to say I don't cover it [sexual morbidity of treatment] in consent at all. I tend to talk about the acute side effects and the late side effects......and within that there's things like about vaginal dryness that get's discussed as a side effect but it doesn't get, you don't then take that on to talk about, and that may then affect you [sexually]......You don't tend to discuss it because there's a lot of other things you are discussing at the time when you consent people....."

[HCP06: Female specialist registrar]

Some women had difficulty providing a detailed account of the information they had received and commented on the effects of anxiety and information overload on their ability to take in and respond to information given to them at what was often a stressful time. This is clearly a strong argument for the greater adequacy of written materials to support or at times supplement patient information given verbally and perhaps for the inclusion of a partner to also listen to what is being discussed.

Where the woman and her partner had both been interviewed regarding information provision, and the couple had been present at routine consultations, it was possible to identify where discrepancies in recall may have occurred. Within the data there was evidence of such a discrepancy solely for PT07 and PTNR03, with the remaining four couples corroborating each other's accounts of this aspect of clinical practice.

"Researcher: Did they tell you that there would be any effect on the vagina itself, do you remember them mentioning that at all?  
PT07: Eh, no. No, I don't remember that.  
Researcher:.....has anyone ever asked you whether or not your sexual life is getting back to normal?  
PT07: No, no-one's ever asked.  
Researcher: .....you have been in a trial, the EXPERT trial and there's a question on those toxicity sheets, yeh?  
PT07: Yes  
Researcher: So did they ask you questions [about your sexual life]?  
PT07: I don't think they've even asked questions on that. They asked you if you can walk here, and you walk there, and can you do your own shopping and all that sort of thing but...."  
Researcher: I take it then that no-one at any point gave you any kind of written information or a point of contact that you could make to find out more about how your treatment might affect your sex life?  
PT07: No, not so far as I know. I mean there was so much going on.

This 63 year old woman (PT07) was interviewed 12 months after completion of neo-adjuvant chemo-radiotherapy followed by an abdomino-perineal resection of the rectum and permanent stoma formation. She had been treated in two different hospitals, the cancer centre for her radiotherapy and overall treatment follow-up and a neighbouring
NHS Trust for her surgical management and subsequent stoma care. Data from her husband’s interview (PTNR03) indicated that when he had been present she had been asked about sexual concerns by the stoma nurse, had received information about the potential impact of radiotherapy on her sexual function from the radiotherapy department nurse who gave feminine care advice at the cancer centre and been asked how the couple’s sex life was by a doctor in the cancer centre during follow up.

Her husband explained how he felt after learning his wife had had part of her vaginal wall resected in order to remove the rectal tumour adequately. This had been mentioned to the woman only on the day of her surgery during the immediate post-operative period and not elaborated upon subsequently:

“I think to be honest I was totally stunned after the operation when, when I really knew then that that was the end of our sex life, basically......And I don’t know if [wife’s name] case is unusual because, because of this vagina business, you know, it wasn’t explained to us that could happen before [the surgery] which maybe, I mean I’m not blaming anybody, I’m not criticising anybody er, perhaps when the surgeon done the job that’s the only way to do it and perhaps that doesn’t happen to everybody but......

No, so if that hadn’t happened I feel we could be back on to a sexual relationship, a full sexual relationship. But I don’t, I don’t know that there’s anything more you can do other than perhaps to warn people that these sorts of things can happen.

It would, what can I say, I really didn’t get an answer from the doctor [at the cancer centre], once I told her we didn’t have a sex life......That would have been helpful if she’s said, “well why not?” when I answered because she could,.....yeh, perhaps said, well try this, do that or tough luck mate, your luck’s run out! The point was I felt really she asked the question expecting me to say, oh it’s getting better and when I said, we ain’t got one [a sex life] she....she sort of looked and just went why not?”

[PTNR03: >60 yr old gentleman married to PT07]

There were contradictions in the interview accounts from health professionals and from women regarding the topics believed to have been discussed by doctors in follow-up consultations (see Tables 6.1 and 6.2). Table 6.2 offers a summary of the information topics said to be omitted at different time points that were specifically mentioned by health professionals, patients and partners in study interviews. The omitted topics solely mentioned by partners are in bold.

There were also contradictory accounts in relation to the extent to which women felt they had been alerted to the possibility of vaginal changes such as stenosis, shortening and bleeding, particularly where this treatment side effect had subsequently proved to be to be severe enough to prevent sexual intercourse or to be considered permanent by the woman.
"There was a massive amount of paperwork and stuff and things that I had to sign saying I accept that this might happen. But nobody mentioned your vagina. No! ....And looking back on it I sort of, I didn’t realise…now I do, that it’s just how, how bad radiotherapy is. The scarring I’ve been left with, you know, the fibrous tissues inside and all the on-going problems I know I’m going to be stuck with for the rest of my life. Yes, I needed information and didn’t really get it. And the problem is, I mean I’m not adverse to ask for it, but if you don’t know what it is, you don’t know what to ask for, you can’t ask the questions…..but nobody said anything about it would damage my vagina, so the whole concept of the fact, you know, and it’s your sex organs!" [PT03: 55 yr old woman, 8 months post surgery / radiotherapy for endometrial cancer]

Table 6.2: Information Topics not discussed / not adequately discussed during consent, on-treatment review and follow-up

<table>
<thead>
<tr>
<th>Patient / Partner Omissions (n = 29) Research Site A only</th>
<th>Health Professional Omissions (n = 20) Research Sites A &amp; B</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Normal pattern of pelvic late effect development</td>
<td>▪ Detailed information about radiotherapy late effects e.g. time frame for development &amp; stabilisation of late effects</td>
</tr>
<tr>
<td>▪ Permanent radiation induced tissue damage</td>
<td>▪ Vaginal Toxicity (particularly stenosis) for women with rectal / anal cancer</td>
</tr>
<tr>
<td>▪ Vaginal changes related to radiotherapy</td>
<td>▪ Feminine Care Provision for women with rectal / anal cancer (site B only)</td>
</tr>
<tr>
<td>▪ Vaginal scar tissue formation, duration &amp; resolution</td>
<td>▪ Sexual Morbidity, particularly for women with rectal / anal cancer</td>
</tr>
<tr>
<td>▪ Vaginal bleeding: normal vs. abnormal</td>
<td>▪ Non-physical aspects of sexual morbidity e.g. desire / orgasm</td>
</tr>
<tr>
<td>▪ Inconsistent vaginal dilator provision (n = 4)</td>
<td>▪ Referral pathways for women with treatment related sexual difficulties</td>
</tr>
<tr>
<td>▪ Sexual impact of treatment</td>
<td>▪ Sexual Counselling Services</td>
</tr>
<tr>
<td>▪ No / inadequate written information re sexual impact of treatment</td>
<td></td>
</tr>
<tr>
<td>▪ Prevalence of sexual difficulties after pelvic radiotherapy</td>
<td></td>
</tr>
<tr>
<td>▪ Interventions for sexual difficulties</td>
<td></td>
</tr>
<tr>
<td>▪ Availability of clinical nurse specialists in gynae-oncology / colorectal cancer</td>
<td></td>
</tr>
<tr>
<td>▪ Cancer centre contact points to address sexual concerns</td>
<td></td>
</tr>
<tr>
<td>▪ Sources of support / counselling re sexual concerns</td>
<td></td>
</tr>
</tbody>
</table>

At the time of treatment consent the development of vaginal dryness was commonly referred to, whereas the possibility of vaginal stenosis and shortening were more likely to be addressed at the time of giving “feminine care advice” during radiotherapy treatment. The amount of detail given to women about vaginal toxicity and the potential for sexual implications varied considerably depending on the individual practitioner providing this
information. This was illustrated by women's recall of the information they had received both at the time of treatment consent and in relation to the rationale given for vaginal douche and dilator use.

“Researcher: So how was the notion of dilators introduced to you by her [radiotherapy nurse]?
PT23: She just said that because of the radiotherapy, I am trying to remember.....because of the radiotherapy, ehm, to just, to get you back to normal. Ehm, you know, you must use these, ehm, but nothing [about sex], I had no idea what was going on.....none at all!”
[PT23: 58 yr old woman, 29 months post chemo-radiotherapy for anal cancer]

Women treated for a rectal or anal cancer were particularly likely to have discussions about vaginal toxicity omitted from the consent and follow up stages of their care, the only reference to vaginal toxicity tending to be during their “feminine care” discussion with the radiotherapy department nurse. Many of the women with non-gynaecological cancers commented on the fact that the possibility of damage to their vagina had never occurred to them as it was not that part of their body that was being treated.

“PT08: Because first of all, as I said, it didn't even occur to me I might [have sexual difficulties], no.... It [sex] was only touched on very very vaguely.
Researcher: What, when the dilators were being given?
PT08: Yeh. And when she explained what could happen [to the vagina] I thought, God, it never occurred to me, so it would be useful to know a bit more.”
[PT08: 58 yr old woman, 6 months post chemo-radiotherapy for anal cancer]

Health professionals also acknowledged that the vaginal and sexual implications of pelvic radiotherapy for this group of women did not have the same service profile as they perceived it had in the management of women with a gynaecological cancer diagnosis.

“You know it's [the vagina] just in close proximity and I think we, we as physicians also tend to concentrate more on the er, you know the sort of GI side effect rather than anything else because they tend to be more problems acutely, which will you know, can cause problems with patients like maybe forcing a delay in the treatment etc.......So I think ehm you know it's, it's ehm inherently on our part where we tend to dodge the issue [vaginal toxicity] and inherently patients tend to forget because they've got a, you know, got a cancer in their back passage and that's really what they tend to see rather than the fact that ehm, you know, if it's a female where the vagina's next door!”
[HCP14: Male specialist registrar]

This comparatively lower profile of both vaginal toxicity evaluation and sexual morbidity discussion for women with non-gynaecological cancer was not clearly demonstrated from
the participant observation data, but this could be explained by the relatively small number of observations in colorectal clinics (n = 19 / 27.5% of observed consultations) and the fact that the overall prevalence of sexual (n = 17 / 25% of observed consultations) or vaginal toxicity discussions (n = 29 / 42% of observed consultations) was so low (section 5.2).

Where information about vaginal toxicity had been given, the level of detail offered in terms of the sexual impact of these vaginal changes and symptoms was often considered vague, brief and inconsistent by health professionals, women and their partners. This criticism was also made regarding the written materials available to women at both research sites, where booklets were offered about radiotherapy to the female pelvis, brachytherapy and feminine care.

"You provide them with a booklet which I feel is insufficient but the booklet sort of skims it in such a, think in about one centimetre, one sentence rather. Ehm, so it's difficult, because I think again you would imagine that it would be covered by the radiotherapists, the girls down actually on the machines, ehm, yeh, so not a huge amount [of information] down the line, I mean that's my personal experience, that's when we really need to be maybe doing a lot more than we are."

[HCP12: Female clinical nurse specialist in gastro-intestinal cancer]

Logically where there had been no or limited discussion of the sexual implications of psychological, hormonal and vaginal changes associated with the women's diagnosis and subsequent treatment it followed that health professionals largely agreed that information about sources of sexual or relationship counselling services and specific referral routes for women with sexual difficulties were not known by practitioners and thus not communicated to women and their partners. Indeed some health professionals cited lack of awareness of specialist services or resources in their locality as one of a number of complex reasons why they tended not to discuss sexual implications of treatment with women for fear of not being able to respond adequately to further questions such a discussion may raise.

"Well I would have to admit that I don't know of the actual referral pattern [for treatment related sexual difficulties] here. And it, it hasn't been something I've, it's been something I've looked for in other aspects of care, but in sexual issues it hasn't been made known to me. And that's obviously a deficiency, it should have been, you know.
....You don't discuss those pathways at consent because you don't know, I don't know what they are. Ehm, but the presence of, you know, a poster on the wall saying 'ring so and so for this', would definitely make me discuss [sexual concerns] more often."

[HCP03: Male clinical research fellow]
This point is explored in more detail in the data categories “Talking sex” in the clinic (chapter nine) and Assessing the sexual consequences of cancer therapy in practice (chapter ten).

However, what may be considered more worrying for patients and their partners was that women stated they did not feel they knew who to contact within their treatment team should they have a sexual concern or need for additional information and that the provision of contact details within the cancer centre was not actively offered to them. This included many of the women being unaware that they could access the clinical nurse specialists associated with either gynaecology or colorectal cancer treatment.

“I mean just from the on-line chatter with other women they often go ‘My gynae nurse’ they all seem to have a gynae nurse. I mean I never had a sense that I ever had a gynae nurse that was marvellous and you could ask anything to which obviously that’s something that fulfils....that’s a good thing for other women that happens somewhere. There was no-one’s face who I could see.....that was there, that was in the hospital, yeh!” [PT01: 45 yr old woman, 21 months post chemo-radiotherapy for cervical cancer]

A number of health professionals who had experience of managing male patients receiving pelvic cancer treatment commented on the apparent gender bias inherent to clinical practice whereby male patients receiving pelvic radiotherapy for bladder, prostate and to a lesser extent rectal or anal cancer were informed of the likelihood of erectile dysfunction associated with their treatment whereas the profile of treatment related female sexual dysfunction was not considered to be as high.

“Ehm I don't think that our [consent] form covers very well, ehm, for females. I think it sort of in a way is a little bit better for males in terms of talking about impotence and sexual dysfunction, I don't think it really covers it for females, it just talks about ehm, you know, menopause and there's nothing in there about ehm, you know, vaginal tightening or shortening or dryness. And of course there is a kind of separate leaflet [feminine care booklet] about that which they, they should be getting but it's whether or not they all systematically do get is a bit less clear. Ehm and it's difficult because on our consent form it's how much detail to go into on any sort of various aspects that we are covering?” [HCP08: Female consultant clinical oncologist]

As discussed within the sub-category Limits of the biomedical gaze (section 6.4), health professionals also mentioned that they found discussion of the “physical" aspects of sexual difficulties easier to address with women compared to elements of sexuality such as sexual desire, orgasm, sexual satisfaction or issues related to femininity or body image.
“No I don’t tend to cover issues like ability to reach orgasm and so on. Usually those things tend to be most affected by surgical procedures but, ehm, I mean radiotherapy does affect it and I must say it’s not something I usually talk about unless the patient were to bring it up, and then I’d be happy to talk about it.”

[HCP02: Male consultant clinical oncologist]

“Well I think, ehm, that, that the sort of easiest parts [in talking about vaginal changes and sexual implications] are around the sort of physical....the sort of obvious physical changes around vaginal changes in terms of shortening and ehm narrowing and those sort of things.... And I think that there does need to be something about libido and ehm, the just general sort of changes in the tissues in the area that might affect ehm, you know, pleasure, ehm.”

[HCP08: Female consultant clinical oncologist]

6.3.1 Documentary Analysis of Patient Consent Forms and Relevant Patient Information Booklets

During the period of participant observation (Sept 2005 to Jan 2006) examples of consent forms and patient information booklets routinely given to women at both research sites were collected for documentary analysis to establish the main focus of written materials used in consultations with patients at the two key patient information delivery points at treatment consent and during radiotherapy treatment.

Treatment Consent

At the time of obtaining written informed consent for pelvic radiotherapy women at research site A were given a pre-printed radiotherapy site specific consent form that identified topics the health professional was expected to discuss and identified patient information booklets produced by CancerBacup and the Cancer Centre recommended to support the verbal explanations by the medical treatment team.

At research site B women were offered a standard consent form that is used within the NHS Trust for all treatments and investigations that require written informed consent. The precise content of the form is dictated by the focus determined by individual practitioners and the limited space available to record treatment information on the form. No patient information booklets are pre-determined as an essential component of the consent process but brief patient information leaflets produced by the cancer centre were provided at the discretion of the practitioner conducting the consultation.

During Pelvic Radiotherapy

At research site A, a separate feminine care leaflet was normally given to women during the first week of their pelvic radiotherapy to accompany a verbal discussion of the use of
vaginal douche for vaginal cleansing during radiotherapy and advance notice of the provision of vaginal dilators for use on conclusion of radiotherapy. Verbal information about the use of vaginal douche and dilators was normally provided by staff nurses (HCP07 and HCP11) based either in the radiotherapy department or in the out patient clinics (HCP15). Routine contact with clinical nurse specialists (CNS) in either gynaecology (HCP09) or colorectal cancer (HCP10) did not occur for these women who were all receiving their treatment as outpatients. Contact with the CNS was normally initiated by medical staff from the follow up clinics if they detected a specific clinical problem that they felt would be best addressed by one of their specialist nurse colleagues.

At research site B the information about feminine care appeared to be verbal only and normally delivered by one of the therapy radiography staff (HCP 16 and 17) and expanded upon for women with cervical or endometrial cancer by the network gynaecology clinical nurse specialist. This CNS (HCP04) was identified particularly to see women with a gynaecological cancer diagnosis who had specific concerns regarding fertility, menopause or sexual function. She regularly attended the gynaecology follow up clinics alongside medical colleagues. Women with an anal or rectal cancer were routinely seen by a colorectal CNS (HCP12) at the time of diagnosis who offered information about the surgical management of their illness with the radiotherapy or chemo-radiotherapy information being given by the therapy radiographers.

Table 6.3 offers a summary of the content of the consent forms and patient information materials available at each research site. Regarding the pre-printed site specific radiotherapy consent forms in use at research site A, infertility and early menopause as a side effect of external beam pelvic radiotherapy for all sites in pre-menopausal women was included. It was interesting to note that although vaginal toxicity and female sexual difficulties were not mentioned, risk of impotence was included for male patients receiving external beam radiotherapy treatment to the bladder or rectum but not to the anal region. As can been seen from table 6.3, information about vaginal toxicity was relatively well addressed in the feminine care leaflet (research site A) but the sexual consequences of such changes tended to be vague, brief and women were requested to approach their treatment team for further advice and sources of support. This was despite the fact that health professionals in oncology were not aware of appropriate referral pathways, sources of expertise or sexual counselling for women experiencing sexual fears or difficulties.
Table 6.3: Content Analysis of Documentary Sources from Research Sites A and B regarding inclusion of information about Vaginal Toxicity and Sexual Implications

<table>
<thead>
<tr>
<th>Consent Form Content</th>
<th>Patient Information Leaflet Content</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Research Site A</strong></td>
<td><strong>Research Site A</strong></td>
</tr>
<tr>
<td><strong>External Beam RT (Gynaecology):</strong></td>
<td><strong>Radiotherapy Booklet</strong></td>
</tr>
<tr>
<td>• Pubic Hair Loss</td>
<td>• Vaginal Dryness</td>
</tr>
<tr>
<td>• Vaginal Dryness</td>
<td>• Vaginal Narrowing</td>
</tr>
<tr>
<td>• No mention of Sexual Implications</td>
<td>• Sexual Discomfort &amp; Lubricants</td>
</tr>
<tr>
<td><strong>Brachytherapy (Gynaecology):</strong></td>
<td>• Reduced Sexual Interest during Radiotherapy</td>
</tr>
<tr>
<td>• Vaginal Soreness</td>
<td>• Further Reading</td>
</tr>
<tr>
<td>• No mention of Sexual Implications</td>
<td><strong>Feminine Care Booklet:</strong></td>
</tr>
<tr>
<td><strong>Bladder:</strong></td>
<td>• Decreased vaginal tissue elasticity</td>
</tr>
<tr>
<td>• Pubic Hair Loss</td>
<td>• Vaginal Fibrosis</td>
</tr>
<tr>
<td>• No mention of Vaginal Toxicity</td>
<td>• Vaginal Dryness</td>
</tr>
<tr>
<td>• No mention of Sexual Implications</td>
<td>• Vaginal Tenderness</td>
</tr>
<tr>
<td><strong>Rectal:</strong></td>
<td>• Vaginal shortening &amp; narrowing that may be permanent</td>
</tr>
<tr>
<td>• Pubic Hair Loss</td>
<td>• Vaginal intercourse, dilator or vibrator use to stretch vagina</td>
</tr>
<tr>
<td>• No mention of Vaginal Toxicity</td>
<td>• Bleeding after dilator use or intercourse</td>
</tr>
<tr>
<td>• No mention of Sexual Implications</td>
<td>• Vaginal lubricant use</td>
</tr>
<tr>
<td><strong>Anal:</strong></td>
<td>• Impact of fatigue on sexual interest</td>
</tr>
<tr>
<td>• Thickening of tissue in ano-genital area</td>
<td>• Trying different sexual positions if sex uncomfortable</td>
</tr>
<tr>
<td>• No mention of Vaginal Toxicity</td>
<td>• Myths about sex and cancer and radioactivity</td>
</tr>
<tr>
<td>• No mention of Sexual Implications</td>
<td>• Advice to contact doctor / nurse if there are concerns about physical relationship with partner</td>
</tr>
<tr>
<td><strong>Research Site B</strong></td>
<td><strong>Brachytherapy:</strong></td>
</tr>
<tr>
<td>Standard Consent Form completed by hand</td>
<td>• States women are unlikely to feel any side effects from this treatment.</td>
</tr>
<tr>
<td><strong>Research Site B</strong></td>
<td>• No mention of Vaginal Toxicity</td>
</tr>
<tr>
<td><strong>Radiotherapy to the Female Pelvis:</strong></td>
<td>• No mention of Sexual Implications</td>
</tr>
<tr>
<td>• Decreased suppleness of vaginal wall</td>
<td><strong>Brachytherapy:</strong></td>
</tr>
<tr>
<td>• Vaginal narrowing</td>
<td>• States women are unlikely to feel any side effects from this treatment.</td>
</tr>
<tr>
<td>• Discomfort associated with sexual intercourse</td>
<td>• No mention of Vaginal Toxicity</td>
</tr>
<tr>
<td>• Difficulty with future vaginal examinations</td>
<td>• No mention of Sexual Implications</td>
</tr>
<tr>
<td>• Indicates further information will be provided regarding use of intimate lubricants and dilators</td>
<td></td>
</tr>
</tbody>
</table>
6.4 Limits of the Biomedical Gaze

A sub-category that emerged from the data regarding the consultation focus during follow up was that the discussion between the health professional (usually a doctor) and the patient tended to be largely biomedical in nature. Many health professionals and patients both anticipated and expected this to be the case given the perceived purpose of the follow up system to detect disease recurrence, evaluate treatment efficacy or to identify and manage physical side effects of treatment. However, some participants lamented the fact that such a narrow biomedical view of patient's problems could lead to the omission or perhaps even the neglect of women's emotional and psychosexual support needs.

"I don't know, I came to associate the [cancer centre] with all the clinical stuff, the treatment, I didn't, maybe that was due to my experience, I didn't associate the [cancer centre] with kind of like getting the emotional support. But maybe if it had been, then I'd have had a good experience, if say [gynaecology CNS] had been based in the [cancer centre] hospital it maybe would have been different. And there was a lack of clarity really as to who was the most appropriate person for me to talk to about this [sexual concerns] because even when you go for the check up it's still very much about the clinical side of it, you know the internal examination, how you're healing and all that stuff. I mean I felt able to bring up the HRT thing but I kind of felt, it all feels a bit rushed when you go in..."

[PT12: 42 yr old woman, 14 months post chemo-radiotherapy for cervical cancer]

Health professionals identified a number of organisational and individual factors that contributed to the biomedical focus of consultations. These included the time available for follow up consultations, the influence of disciplinary orientation and professional education and the role expectations of some health professionals, patients and partners attending the clinics.

"...I think in some ways in a busy clinic that's important because it's got to be about the disease and very often, in terms of psychosocial issues, in terms of chronic side effects there should be, I would feel there should be more of an emphasis upon late side effects, sexual and whatever others. In terms of psychosocial issues, often the doctor is a poor person, or the worst person you could talk to about, because certainly there isn't an appreciation of issues like that and apart from referral on to someone else, which I suppose is an important axis of referral, but really, ehm, it, it's often a poor person to talk to anyway about such issues......do you know what I mean?"

[HCP03: Male clinical research fellow]
"...I would imagine that the outcome is clearly of a traditional approach to medicine, if something's wrong with you, you say we're going to fix you."

[PTNR01: 41-50 yr old gentleman married to PT09, 50 yr old woman, 12 months post chemo-radiotherapy / abdomino-perineal resection for rectal cancer]

However, there was also a suggestion that one organisational reason for not addressing emotional or sexual elements of a patient's well-being related to a lack of knowledge about the resources available in that locality to refer women to when such support needs were identified.

"I would rather refer to someone than get into in-depth discussion because on the one hand the time and number two, I don't think I'm a person qualified to talk to like that. You know, I think I'm, I'm qualified for the medical bits of it, you know....I would like to think that I will, I will refer on but ehm, obviously I haven't been because there isn't, I don't know a referral pattern."

[HCP03: Male clinical research fellow]

In exploring the data extracts relating to this sub-category there was no obvious difference in the extent to which nurses, doctors or radiographers adopted a dominant biomedical gaze to their clinical assessment during on-treatment review or in follow up. A gynaecology clinical nurse specialist (HCP09) explained how she made explicit links between the anatomical and physiological organ changes following pelvic radiotherapy and the implications for sexual function:

"I'm talking about the size of the vagina and using it really, not just that it may be smaller but, you know, whether you can and can't use it."

[HCP09: Female clinical nurse specialist in gynaecology]

However, the emphasis within her consultation was still on the biomedical and functional aspects of treatment related sexual morbidity as opposed to relationship or psychological elements. The focus on physical function was reiterated by a colorectal clinical nurse specialist (CNS) from site A, who explained “...we have such a medical model of approach to patient care.” [HCP10] and corroborated by another colorectal nurse specialist [HCP12] from site B in describing the patient management approach dominant within her team:

"...I would first try and make sure there's nothing physical and if there isn't anything physical, ehm, then you probably would have to look for someone in, not necessarily counselling, but it's really trying to find the crux of the matter."

[HCP12: Female clinical nurse specialist in colorectal cancer]
While this specialist nurse demonstrated awareness that sexual consequences of treatment had contributing factors beyond the physical domain, she did not appear to consider the relational or psychological aspects of sexual morbidity appropriate for her to address but would seek to triage patients to specialist counselling following assessment. However, what was not clear was whether the tendency to separate the physical care aspects from women’s psychological support needs was a feature of individual / professional training or confidence or something also endorsed at an organisational level through service provision and the delineation of professional roles. This was illustrated by a therapy radiographer who was interested in providing psychosocial support to women she encountered, but perceived this was currently not available within the Trust where she worked:

*Researcher:* “Would there be anything that you would like to see added that isn’t currently available for the women that you are caring for?”

*HCP 17:* “Yes, some official way of looking after the social and psychological side of it…..And particularly with their partners, if they’ve got them.”

[HCP17: Female therapy radiographer]

When sexual issues were discussed in practice there was also the suggestion that where a health professional appeared uncomfortable with this aspect of patient recovery after radiotherapy, maintaining a focus on biomedical issues could be used as a communication strategy to manage their perceived embarrassment.

“…Yeh, you know, it was sort of, it was her way of coping with that [talking about sex] by not sort of having eye contact, that she, she was very much on the medical side and you know, she says, Oh yes you can have sex, that’s alright, ehm, enjoy it. But there was still no eye contact about her, she was still at her desk, you know sort of thing, and eh don’t forget to use, you know, to do the douching….are you doing the douching? Every time she saw me. So it was very much on the physical side, you know the medical side, I would say…..so not sort of interested, I would think, in your emotional side.” [PT14, a retired social worker, talking about a Radiotherapy Nurse]

Analysis of participant observation data (section 5.1) from follow up clinics corroborates with data emerging from interviews with health professionals, women and their partners. Psychosocial topics accounted for consultation content in only 42% of consultations, compared to the prevalence of discussions about bowel toxicity (81%) and bladder toxicity (70%).
Although this data sub-category contributes to defining the culture of the follow up clinic, it could be argued that dominance of the biomedical gaze in clinical assessment and management may also define how female sexuality is framed or viewed within clinical oncology.

6.5 Fear of Disease Recurrence

Cancer as an illness has the capacity to create fear in those affected for years after treatment has been completed because of its propensity to spread from its original site and to recur, often after many years. This knowledge has become part of a shared understanding about the threat posed by cancer within society and so even when an individual has an extremely low risk of recurrence of their disease, the fear of recurrence is a common experience. Thus detection of recurrence is, as outlined in the sub-category Information Priorities during follow up, seen as a key priority during medical follow up clinics.

Given the anxiety regarding cancer recurrence it is perhaps understandable that women, partners and health professionals find it difficult to address aspects of a woman's recovery and rehabilitation after cancer that some may not consider essential to their survival or central to their day to day quality of life. As the following excerpts from participant's transcripts illustrate, fear of recurrence is a pervasive experience for many women and overshadows their medical consultation until disease remission is confirmed.

“So the next time I went [to follow up clinic] it was my consultant. And he looked at the notes [medical record] and I told him about the bad back and I said, well I thought I'd got secondaries, and he said well you would, wouldn't you! And I thought well you've summed me up very well. [laughter]”
[PT06: 72 yr old woman, 12 months post surgery / radiotherapy for endometrial cancer]

“And I remember one time I, I was having headaches and things as well and I was having chemotherapy and I did say that time because I was going to, the trouble is you are always convinced it's cancer whatever ache and pain you get you are always convinced it's the cancer gone somewhere. And I said to him I think, ehm, I think I've got ehm a brain tumour. Well he laughed. He said I'm really sorry this is a really inappropriate reaction, I know that you're worried about it but, he said, you have no need to worry, there's absolutely no possible way, you haven't got one symptom. He went through the symptoms, he went through it all and I think the fact that he laughed was enough, you know, to convince me that. Did stop me worrying about it I must admit.”
[PT17: 67 yr old woman, 15 months post chemo-radiotherapy for bladder cancer]
The fear of recurrent disease often meant that when medical staff suggested that a reduction in frequency of follow up clinic attendance was warranted, some women resisted this suggestion as they saw their regular check ups as security against the cancer returning.

"So then I was coming up every three months just to get my bloods done and then..., now when did I come up before, February it must have been, they said they want to reduce it to six months, the bloods, but I said Oh no, I like to come every three months.

Because somebody said to me that if my cells change they might tell in the bloods so that's why I like to come and have that extra bit of...[security]."

[PT20: 33 yr old woman, 22 months post chemo-radiotherapy for cervical cancer]

For other women certain symptoms were linked with the fear of recurrence as they had been the sign that prompted the woman to seek medical advice and that led to confirmation of a cancer diagnosis in the first instance. This could impact negatively on both rehabilitation strategies and their sexual recovery when a particular symptom, in this instance vaginal bleeding, and sexual activity were connected in some way as this woman explains:

"PT21: Every time I do it [vaginal dilation], because I suppose it was bleeding that was the instigator.

Researcher: That was the symptom...

PT21: The symptom... that I am looking always for that. And I think I, in the same, that is why I feel intercourse would not, it would just be, it wouldn't be enjoyable for anybody to have it because to me it would be something that I would be looking all the time, gosh, you know, is that alright, is that not alright, and therefore you can't actually forget it.

......It's still this feeling of always looking for symptoms, and when somebody says to you, well you know you have to get to five years and then you go to ten, of course you're looking and it, ehm, and in a way I really just want to try and forget about it and get on with life and that becomes harder with that, I mean all the time between the times [attending clinic] I can forget about it, but all the time you do this dilating (laughter) is...... OK I don't"

[PT21: 54 yr old woman, 18 months post chemo-radiotherapy for cervical cancer]

The woman and researcher laugh together at this point because the woman is aware she has just contradicted herself in that she had already disclosed to the researcher that she did not use the vaginal dilators regularly because she did not want to be reminded of her illness on a weekly basis. The Meaning of blood to this group of women will be explored further under the data category of Vagina Monologues in chapter seven.
Other women made a link between dyspareunia and fear that this may signify the recurrence of their illness, seeking alternative explanations for their experience of pain during sexual activity:

“And also, you know, you do have that thing at the back of your mind, Oh God, why am I uncomfortable when it’s on penetration, why? You know, so and there could be sort of, your fears could be allayed a little bit maybe. I mean, you know, it might not be from the radiotherapy that I am sore it might be from going through the menopause, it might be from, er, a hormonal thing say with the menopause, it might be like ehm,a, ehm, you know, mentally your freezing you know, it could be that. Ehm, I don’t know, I’ve got nobody to relate to or bounce it [her explanations about the pain] off!”

[PT22: 51 yr old woman, 31 months post surgery / radiotherapy for cervical cancer]

“And I was concerned about whether I did have something because the pain [when attempting intercourse] just ripped through me, it was terrible!”

[PT24: 54 yr old woman, 12 months post chemo-radiotherapy / anterior resection for rectal cancer]

It is therefore not unreasonable to consider that the associations between sexual activity and the women’s cancer through their experience of symptoms such as pain or vaginal bleeding may in itself lead to anxiety surrounding sexual expression and increase the likelihood of reduced sexual desire or avoidance.

Partners were also aware of this fear in their wives, with one partner buying a holiday home for his wife in order to encourage her to reduce her worry about disease recurrence when they had been told there was a higher risk of this occurring.

“I think they [medical consultations] were initially, sorry, they were initially I think, ehm, it was quite a traumatic experience obviously and she was never sure what was going...she was going to be told.”

[PTNR01: 41-50 yr old gentleman married to PT09, 50 yr old woman, 12 months post chemo-radiotherapy / abdomino-perineal resection for rectal cancer]

“And actually the reason I bought the house.....I wanted her to have something that was out in the future. That was, she could focus on and think about other than the thought that she might die or the cancer might reoccur...”

[PTNR04: 51-60 yr old gentleman married to PT16, 56 yr old woman, 24 months post surgery / radiotherapy for endometrial cancer]

One consultant clinical oncologist felt that at times women focused excessively on specific side effects of their treatment during follow up discussions in order to avoid talking about the topic they feared most, that of the risk of recurrence:
"Ehm, and ehm you know they may really be pulling the wool over their eyes and I think sometimes it's almost a deliberate obfuscation of their real worries to come in any focus of, ehm, side effects, when really they have a very good reason to be focussing on the chance of recurrent disease. So, ehm, I think sometimes they, they change the, ehm, sort of focus of the visit in order to, you know, keep away from the thing they don't want to hear about."

[HCP02: Male consultant clinical oncologist]

Awareness of the threat of recurrence was also a factor that influenced how health professionals conducted follow up discussions. One specialist registrar explained how the patient's agenda could influence the content of a consultation or where the focus of a consultation could rapidly shift from one where it was appropriate to enquire about sexual recovery to one where this may be deemed inappropriate or insensitive:

"...Because if you're giving information in an environment where the patient's come back, they've got a new symptom, they are worried about relapse....you know a patient comes in very stressed, very anxious, then it, I don't think it's necessarily appropriate at that stage because I think actually, although sexual issues are very important to patients, they come through the door in many ways with a similar agenda to you have, the top of their 'tick box'....has it come back? ....When you examine ladies [vaginal examination], you know, I examined a lady and she bled, she hadn't bled before, first thing that goes through my mind is, I couldn't feel anything, but it was is this relapse? You know, and I said to the patient, do you normally bleed? She goes no, and that was it, the whole, the whole, then it was sort of like...and in that sort of context then you may suddenly find that in that consultation, no matter how much time there is, there isn't room for discussing another issue...."

[HCP05: Male specialist registrar]

What these interview excerpts illustrate is that the medical follow up clinic in oncology is often an emotionally charged clinical environment where the woman and her medical team endeavour to manage the communication process in such a way that the core business of the consultation is achieved in a time efficient manner while still endeavouring to contain the pervasive anxiety associated with these medical encounters.

It is therefore not surprising that the topic agenda for such consultations is co-constructed by patients and health professionals, including concordance about what aspects of the women's illness experience may be deemed central or marginal to the culture of the clinic.
In exploring the experience of follow up care for women who have received pelvic radiotherapy it became clear that the prime vehicle for the delivery of information and clinical services was via the professional relationship between women and their medical team. This would normally be the consultant in charge of their medical management, particularly for private patients attending the clinics, or a specialist registrar normally attached to that team for a period not exceeding 12 months.

While the primacy of the clinical relationship is not at issue, the woman's family and, more specifically, their intimate partner also play a central role in the provision of care and support while women recover from cancer treatment. This may be considered of particular relevance when one is considering the sexual recovery of women post-radiotherapy, where the role of the partner is often pivotal in supporting sexual adjustment following treatment as a gradual return to "normal" or pre-illness activities and roles is anticipated.

While it is routine practice to include partners in sexual assessment within psychosexual therapy or sexological practice I was interested to learn how the inclusion of partners was viewed by participants during oncology follow up consultations, particularly those where discussion of sexual concerns associated with treatment might be expected to take place.

This aspect of communication about sexual issues is explored in more detail within the data category "Talking Sex" in the Clinic (chapter nine) where health professionals identified the presence of partners or other people in the consultation room as a barrier to discussing women's sexual concerns in the clinic setting. Health professionals varied considerably regarding the degree of comfort they experienced in considering talking about sexual issues to couples, as opposed to the woman individually.

"...it does depend on as to whether they are with their partner and how you feel about their interactions, you are watching how they respond to each other and then, is it something you want to talk about in terms...it seems people's husbands are really creepy and you, you do it [talking about sexual issues to woman] on a separate occasion which is difficult because you don't tend to have another opportunity to take a person aside and talk to them, so that would be more as a treatment radiographer I would, I suppose it's going out of the room and maybe veer them [the woman] off into a corner and talk about it then. (Researcher: Right) But because it is quite a private [issue]...”

[HCP17: Female therapy radiographer]
A number of health professionals were either neutral about the partner’s presence during consultations, or actually felt there were times when their presence would have been preferred or beneficial but few appeared to take specific steps to ensure that partners were included in appropriate assessment and communication processes.

“I would say [partners are present] probably 50% of the time and they usually scuttle out of the room the minute there’s going to be a physical examination. I have no fixed views about this...if the patient wants the partner there I am completely happy for them to be there.” [HCP20: Female consultant clinical oncologist]

“The other thing is, you see, we only ever ask the woman these things [about sexual impact of treatment].....You don’t know what strain that’s putting on the partner. Eh, I have had patients say, Oh my poor husband, he misses it [sex] awfully you know, and so I don’t ask him where he goes on a Thursday. He’s probably going to the masons or something, but you know, she thinks he’s off down Soho and that it’s entirely justified and ehm....actually that was a patient where I did address it [sexual concerns] and talked to the two of them because I was worried that this was risking their marriage and I thought that she had misunderstood him.” [HCP02: Male consultant clinical oncologist]

However, the impression gained from the interviews and endorsed by my experience as a participant observer in the clinics was that the focus of discussions was almost always the woman as opposed to the couple, even when the partner was present in the room. Clearly this might be anticipated if the topic focus is predominantly that of the physical effects of the disease and treatment as opposed to the woman’s overall recovery including broader psychological, social or sexual issues associated with the experience of cancer.

Researcher: “Do you ever speak to a couple about it [sexual impact]?
HCP13: “I don’t actually, no, no. I involve the female more than the husband, yes. No I don’t really.......And even in prostate cancer, very often you know the wife sits in, we don’t really address, we don’t really address it [impact on the partner].”
Researcher: “Does that mean you are directing your discussion to the patient and the partner happens to be in the room but she’s not part of the discussion really, she’s just listening in?”
HCP13: “Yes, yes. Yeh, I never, never really thought about turning round to the wife and asking her, how do you feel about that? Maybe I should.” [HCP13: Female specialist registrar]

The above transcript excerpt is particularly interesting because it also seems to imply that although there is a more proactive discussion of male sexual dysfunction following pelvic radiotherapy in prostate cancer, the female partner is also marginalised in discussions about male sexual dysfunction when she is present in the clinic.
It is important to take account of the differing views of individual patients and partners in considering the role of the partner within the clinic context. Some women did not feel they wanted their partners present during discussions they considered private or intimate while others would have welcomed their presence to improve understanding of treatment effects that had an impact on partners.

"...I think, ehm, certainly the women I have talked to have found it a very intimate issue and want to just chat to you in a small room on their own."

[HCP16: Female therapy radiographer]

PT13: "Professionally I don't think he was told about anything. But we just used to go together, he would just come with me and wait for me outside. I would tell him what had been said."
Researcher: "Would you have wanted him to be involved more?"
PT13: "Yes, yes."

[PT13: 32 yr old woman, 16 months post surgery / chemo-radiotherapy for cervical cancer]

Partners also varied in the extent to which they either expected to be included in clinic discussions about their wives / partner's treatment or had actively sought to be present. All of the men interviewed (n = 5) had made a point of being present as often as they could as a mark of their support. One partner, aged 41-50 years, who had developed erectile difficulties following his wife's cancer treatment, was particularly aggrieved about how clinicians ignore the impact of such intensive treatment (his wife had been treated for rectal cancer) on the intimate partner, even when disruption to the couple's sexual life is anticipated. He felt alone in seeking medical support regarding his sexual difficulty which he partially attributed to the disruption of their sexual relationship resulting from his wife's cancer treatment.

"But it [consultation discussion] wasn't focused on us as a couple. .....It was like, thank you for coming but I'm talking to her. .....Hmmm. I would have liked it if it had been specifically addressed to me. And [partner's name] this is the impact it potentially could have on you. And these are the things we can do to help you in your relationship. And that's not been forthcoming. I get the feeling that also that there's a sort of, those times that I didn't go, she was given some information and sort of said, make sure your husband reads this. And the chances of that happening are pretty nil. Not just in my circumstances but in any normal circumstances the fact that I am not here and you know I come home for the weekend and it's a pretty hectic house. Lots going on. Didn't have that....and maybe, yeh, a bit of investigation into my personal circumstances. The fact of the matter is, you know, I took it in my own hands to do something about it" [PTNR01: 41-50 yr old gentleman married to PT09, 50 yr old woman, 12 months post chemo-radiotherapy / abdomino-perineal resection for rectal cancer]
While PTNR02 commented on being excluded from his wife's discussions with health professionals: "...and she was given long advice. Now that was done on a one to one basis, I was outside...", PTNR03 recounted the radiotherapy nurse's embarrassment when he accompanied his wife during a discussion about the vaginal changes that may occur following pelvic radiotherapy and the use of vaginal dilators:

"PTNR03: There was a nurse who took [patient name] aside and said, oh come and see, it was almost unofficial I felt, you know, but ehm and just explained to her that she should use a dilator because if she didn't use a dilator she could get fibrosis, which I didn't even know what it was, so I asked. But after that I never went in to those interviews because the nurse herself seemed a bit embarrassed to have me there.

Researcher: Would you have liked to have gone in, do you think, to have heard?
PTNR03: Yeh..., I wasn't embarrassed when she was talking to [patient name]. I didn't sort of join in but she was...but I just felt she was, er, very pleasant but she made a couple of sort of jokes about me being there, as if it was the first time she'd ever had a man in the room with her when she was talking to a patient about these things, you know. So I didn't go, [patient name] saw her about three or four times I suppose, but I didn't, I only saw her the once.

Researcher: Right, so your sense was that she was a wee bit uncomfortable about you being there.
PTNR03: A bit uncomfortable about it, yeh, yeh indeed."

[PTNR03: > 60 yr old gentleman married to PT07, 63 yr old woman, 12 months post chemo-radiotherapy / abdomino-perineal resection for rectal cancer]

Transcripts from both health professionals and partners did indicate that active inclusion of partners in follow up consultations was not part of routine practice in the clinic and that direct communication with partners was unusual when they were present. Otherwise partners were absent from the clinic room because they had been left outside by the patient, or had exited the clinic room prior to a physical examination taking place.

Hence the role of the partner within the culture of the clinic was one of a supporter for the woman who operated on the margins of the patient / health professional relationship but was not usually actively engaged in consultation discussions.
6.7 A Question of Time

In exploring the culture of the clinic one characteristic that both patients and health professionals felt was an important determinant of clinic process was that of time constraints. The majority of health professionals perceived that clinical discussions with patients were always time limited and that this perception of time availability within the context of a busy clinic shaped the focus of consultations to varying degrees.

The pressure of time management appeared to be consistent across grades of staff and disciplines, affecting consultant medical staff, specialist registrars, clinical nurse specialists and therapy radiographers to a similar extent.

While the medical and therapy radiography staff commented on their personal time demands, the clinical nurse specialists tended to comment on the time pressures dictated to them through participation within the routine of medical follow up clinics. There was no mention of CNS staff running their own clinical service for women.

"And also whether I'm in a hurry or not. How many patients I've got waiting may influence.... And also it takes a long time to talk about it [sexual concerns] if there is a problem, so, yeh...you might skip it if you were in a real rush."

[HCP01: Female specialist registrar]

"...It's partly a time constraint because you can't open up that conversation [about sex] without time.....I think that training would make a difference but I think also the structure of the clinics would have to be different. There really isn't time. I mean you get through those LENTSOMA forms and you come to this thing and it's about vaginal dryness and you think, Oh I just can't do it, I haven't got the, you know, we are already running late and how am I going to start going through this in a way that's one, sensitive and kind and nice and that, that's going to get anything you know, it would take another fifteen minutes, you know, minimum, I haven't got it [time]..."

[HCP08: Female consultant clinical oncologist]

"Because we spend so much time [on delivering radiotherapy], particularly with the huge pressure we've got on to treat people.....Focussing on get them in, get them out, get them in, get them out. And you don't have time to, to talk to the patients as you'd like to......We need longer appointment times then of course which means we need more radiographers so that we can spend longer with the patients."

[HCP17: Female therapy radiographer]

When discussing the experience of follow up clinics, women differed considerably in the extent to which they felt unduly influenced by the busyness of the clinic and time constraints. However, they all expressed an awareness of time pressure and guilt about extending their consultation time.
"Ehm, so yes I think you are aware [about time constraints] and I'm sure, you know, you meet people, I am not particularly backward in coming forward about anything that's wrong with me but I am sure that other people are, are perhaps pressured by the fact that you know they are very busy." 
[PT17: 67 yr old woman, 15 months post chemo-radiotherapy for bladder cancer]

"Ehm. They're [follow up clinics] never as relaxed as we two are now and there's always the pressure of time when you go in to see the doctors. And half the time, you know, they're, I'm sure they are trying to get rid of you before you even get in there [laughter] you know.....and it's, nurse takes you into a room and the doctor appears and go up there [onto examination couch] and you know, take your clothes off and they examine you and, and they've gone and nurse is in and you know, it's like you're on a treadmill, you know, and to be able to sit down, like this, no that's not possible and that's a shame.” 
[PT14: 63 yr old woman, 4 months post surgery / radiotherapy for endometrial cancer]

One woman commented on the contrast between her experiences of the medical clinic at the cancer centre, which she likened to a visit to her GP, to those with a clinical nurse specialist at a neighbouring NHS Trust:

"Ehm, I mean I felt able to bring up the HRT thing [with the doctor] but I kind of felt, it all feels a bit rushed when you go in. Whereas I felt like with [CNS first name], because she had this level of awareness, that my time with her wasn't rushed in any way. She would have given me as much time as I needed. And I would go in knowing that she would be at least available for an hour for me, ehm, and, you know, whereas you kind of feel when you are in the hospital everything feels kind of quite pressurised, like you need to kind of like in and out, like when you go to the GP.”
[PT12: 42 yr old woman, 14 months post chemo-radiotherapy for cervical cancer]

Despite both consultations taking place in a hospital environment, the more protracted time available with the clinical nurse specialist had offered this woman something she felt was missing in her medical consultation. However, as you can see from extracts HCP08 and HCP17 this is less a question of disciplinary bias and more one of recognising the additional time it can take to address more sensitive aspects of practice.

The time taken to address sexual concerns in the clinic was not only influenced by the perceived complexity and sensitivity of the topic itself but, as one specialist registrar explained, the communication strategy adopted in order to reach that discussion topic in a mutually acceptable manner:

“....But when it comes to talking about, you know, personal problems or you know something that can be highly emotional to a, to a particular person, er when it
comes to say things to do with their sex life or any sexual dysfunction or any particular problem, ehm, you will actually find yourself not getting to the point straight away because you have to find a way to get at that point but just talking about other things first and then moving on depending on what your rapport is, and, you know, that's going to take you ten or fifteen minutes, you know that puts sort of a little bit of pressure, so...

[HCP14: Male specialist registrar]

Some women had adopted strategies for ensuring the consultation did address their priority agenda items within the limited time available but still experienced feelings of guilt. While one woman explained that she did not ask about sexual concerns because the doctor would think she was "taking liberties" by asking too many questions and taking up more than her allotted consultation time.

“PT01: I mean I used to carry a hideous notebook which used to frighten everyone from the questions [both laughing].
Researcher: What, out would come this tome?
PT01: Yes, it's like oh god! So I will [ask questions] but, on the whole when I come and see him I always get the impression he's pretty damn busy and, ehm, so you know, I mean like I said, you know when I, if there are questions that need to be asked, I'd ask.”
[PT01: 45 yr old woman, 21 months post chemo-radiotherapy for cervical cancer]

"I was going to actually ask the doctor next time I come about my sexual activity, because as I say I had so much going on because I have had a lot this week.....But then it went, the pain went for a few weeks and of course I said to him [doctor] I don't need to see it now [gastroenterologist] , but of course the pain is back again so by the time you've got all that out I don't like to say ...Oh, and by the way, so and so, because he might think...Bloody Hell! I think he thinks you are taking liberties because you are asking all these questions because you have got these problems and then you put another problem on top [laughs] I don't like to ask [about sexual concerns].”
[PT02: 51 yr old woman, 12 months post chemo-radiotherapy for anal cancer]

It was interesting to note that in analysing the patient interview transcripts coded against this data category none of the five private patients had identified time constraints within their consultations as a factor influencing their experience of the follow up clinic. Furthermore, analysis of participant observation data found no relationship between the number of topics addressed in any single consultation and the likelihood of sexual concerns being raised as a consultation topic despite some health care professionals attributing the absence of any discussion regarding sexual issues as a consequence of the busyness of particular consultations.
Perceived and actual time constraints limiting the discussion of sexual issues within these medical follow up clinics will be further explored as one of a number of factors influencing patient / health professional communication in the category “Talking Sex” in the Clinic (chapter nine).

6.8 Category Summary

The culture of the clinic is explored through data emanating from both participant observation in follow up and on-treatment review clinics summarised in chapter five and interview extracts from patients, their partners and the health care professionals responsible for delivering this clinical service.

The clinic was experienced by staff, patients and their partners as a time-limited consultation context with an agreed priority role to:

- Conduct disease surveillance, particularly the detection of recurrent disease
- Confirm treatment efficacy, particularly inducing disease remission / control
- Evaluate treatment toxicity, particularly acute side effects of radiotherapy / chemo-radiation

Fear of Recurrence was a pervasive, emotionally-laden sub-text that shaped the experience of the clinic for women and their partners. Women talked of their preoccupation with the fear that their illness has returned, particularly if they had been experiencing unexplained symptoms, until the doctor's physical examination had excluded that possibility. Health care professionals in the clinic were aware of the women's concerns and considered the detection and exclusion of persistent or recurrent disease as a priority function of the follow up clinic, especially in the first twelve to twenty-four months post-treatment when the risk of recurrence was highest. Thus the oncology follow up clinic is an emotionally charged environment where patient-doctor communication is managed in such a way that the core business of the consultation is achieved in a time efficient manner while endeavouring to contain the women's anxiety during these medical encounters.

Both real and perceived time constraints (A Question of Time) inherent to the conduct of the clinic also shaped the dominant communication pattern and consultation content. Some women felt constrained or rushed by their awareness of time pressures created by the volume of patient throughput and the demeanour of the doctors and nurses.
with whom they made contact and were thus unlikely to ask questions, particularly those that may be considered marginal to the clinic business or core function. Others adopted strategies to ensure their voices were heard within the medical agenda such as compiling written lists of questions in advance to ask their doctor. Health care professionals also demonstrated an acute awareness of time pressures and often felt less able to discuss topics that they considered complex or time consuming, such as psychosocial or sexual issues associated with the women's illness or treatment.

Patient information about treatment impact and anticipated side effects of pelvic radiotherapy took place at two main time points:

- As part of informed consent prior to treatment
- During radiotherapy, in association with the delivery of “feminine care” advice

This information was planned, led by the health professional and verbal explanation was usually supplemented by written information materials. Treatment late effects such as medically induced menopause and infertility were always addressed at treatment consent with pre-menopausal women but the sexual implications of pelvic radiotherapy was not normally considered an information priority at this time due to the women's high anxiety levels and risk of information overload.

In contrast information exchanges in the follow up clinic were rarely planned or had an inherent structure and tended to be verbal discussion in response to active patient symptoms or problems of a predominantly physical nature. Information priorities were predominantly the acute side effects of radiotherapy / chemo-radiotherapy such as bowel, bladder or skin toxicity and their management. Vaginal toxicity was addressed in brief at consent and elaborated upon to varying extent at the time of feminine care provision but was not a central focus during follow up consultations despite the conduct of vaginal examinations as part of the clinic routine in the gynaecological clinics. In the colorectal follow up clinics the profile of vaginal toxicity was markedly reduced and enquiry or examination of this potential site of toxicity only took place where the women complained of active vaginal symptoms such as bleeding, pain or discharge.

Women experienced the follow up agenda as one where the focus was essentially “clinical” or biomedical and some lamented the perceived lack of interest in their emotional, psychosocial or sexual well-being post-treatment (Limits of the Biomedical Gaze). A number of the doctors commented on their biomedical focus, believing they were not the best person to address emotional or sexual concerns associated with cancer or its treatment. While some of the nurses and therapy radiographers appeared to have a
greater orientation to psychosocial and sexual aspects of patient recovery they were not readily accessible to women during the follow up phase of their illness experience unless a referral was initiated by the doctor conducting their review. Retaining a biomedical focus for consultations was also seen as a coping strategy to enhance time management and reduce the likelihood of experiencing or inducing embarrassment.

Partners were largely marginal to the clinic context (Partner Exclusion) even when they accompanied the women during a consultation. The focus of the consultation was always the woman and not the couple with some health professionals regarding the presence of the partner as a barrier to discussing sexual issues. Partners either accepted their invisibility or wanted greater involvement but experienced health professionals as evasive or embarrassed to have them there, particularly during feminine care discussions.

Health professionals acknowledged that they tended not to discuss sexual issues with women (Information Gaps) due to an absence of agreed referral pathways within the cancer centre and a lack of knowledge about sources of expertise or sexual counselling for women who may experience sexual difficulties associated with their treatment. Women and their partners also commented on their lack of awareness about who to contact if they had a question or concern regarding their sexual well-being and the majority were unaware that clinical nurse specialists in gynae-oncology or colorectal practice were a source of support and information after their treatment had been completed.

Health professionals commented on the apparent gender disparity in their practice whereby there was a more direct and proactive discussion of male sexual difficulties at the time of treatment consent and in the follow up clinic, together with provision of pharmacological interventions for erectile dysfunction. There was recognition that female sexual difficulties were not routinely assessed and managed in an equitable way within the clinic, with this aspect of patient care remaining on the margins of professional awareness, particularly for women with non-gynaecological malignancies.
Chapter 7: Constructions of Female Sexuality after Cancer Treatment

After a confirmed cancer diagnosis individuals are faced with a number of threats to their physical, psychological and social well-being. Many, when faced with the reality of a cancer diagnosis, questioned the prospect of their survival. Being faced with this existential threat often leads to reappraisal of priorities in people's lives and consideration of both the temporary and more permanent changes they may have to accept as a "price to pay" for a greater likelihood of survival.

For women with a pelvic malignancy the treatment induced changes that may need to be considered emanate from the anticipated acute and late effects of surgery, radiotherapy or chemotherapy used to eradicate or control their disease. As discussed in the previous chapter, Culture of the Clinic, treatment with curative intent may result in a range of functional difficulties affecting the every day lives of women and their partners. There are also a number of psychological and social responses to the diagnosis and treatment of cancer, including the potential impact on a woman or couple's sexual life. Exploration of the interview data revealed how facing a diagnosis of cancer and experiencing radical treatment challenged pre-illness views of women's lives in general and placed their sexual lives in a shifting and uncertain illness context.

This chapter considers the ways in which sexuality and sexual recovery is viewed by women, their partners and the health professionals caring for these women following cancer treatment. The sexuality of these women is also explored and constructed within the context of their intimate relationships and their experience of cancer as a life threatening condition.

Constructions of Female Sexuality after Cancer Treatment inevitably overlaps with data categories that are dependent upon individual's beliefs and values regarding female sexuality. One example is the category "Talking Sex" in the Clinic (chapter nine) where data representing factors that act as barriers or enable discussion of women's sexual concerns in the clinical setting are likely to be determined by the personal and social construction of female sexuality held by individuals. These personal and social constructions of female sexuality also shape the behaviours that relate to sexuality in this specific illness context.

Figure 7.1 provides a summary of the sub-categories that contribute to the data category Constructions of Female Sexuality after Cancer Treatment.
While some aspects of these women’s stories were captured on tape as they answered specific interview questions, on many occasions individual accounts found voice only when the digital recorder was switched off. These women’s narratives were then captured more through my field notes and reflexivity as I processed the memories and feelings generated in coming to know these women (albeit in a limited way) as individuals with hopes, fears and aspirations about a life beyond the restrictions imposed by cancer.

7.1 The Cost of Survival

During interviews women often spent time recounting their personal stories about how their cancer had been found and what this diagnosis had meant to them emotionally within the context of their relationship and family lives. A number of women also spoke specifically about how their sexuality was viewed by them when considered in the context of their survival.

"....at the time when you first come into contact with people you just think...Am I gonna die?...Am I gonna die?......Sex is, come on, forget it! Don’t care if you never had sex again!" [PT01:45yr old woman 21 months post chemo-radiotherapy for cervical cancer]
In talking about symptoms women had endured as acute treatment effects it was clear that the discomfort, disfigurement and inconvenience of their side effects were considered "...a small price to pay for getting rid of the cancer" (PT17), clearly the ultimate goal for patients, partners and health professionals alike.

"Yes, because I couldn't eat, I couldn't, I would dread going to the toilet because well my radiotherapy was at the back and at the front so I had burns on my bottom which made it almost impossible to go to the loo. But, ehm, I can't complain, I can't say it was a bad thing to do because the disease so far, so far I am fine. The doctors are saying that everything is looking great which I'm happy about. It's the side effects I will always remember, but I don't complain..."

[PT13: 32 yr old woman 16 months post surgery and radiotherapy for cervical cancer]

"....I think that it's, you know, has it [cancer experience] changed our relationship? I don't think it's changed our relationship, not in a, not in a, well I don't think so, I think that the way I see it is that, I guess and most people must say it, I'm glad she's alive and I'm glad that she has recovered." [PTNR04: husband of 56 yr old woman (PT16) treated for endometrial cancer]

".....they're so grateful they're alive because they've heard the word cancer and they think they're gonna die. It's when they actually survive then they start realising about the side effects and how much they are affecting them, and focus on that." [HCP01: Female specialist registrar in clinical oncology]

The majority of women and partners interviewed commented on the lack of importance they attributed to sexual well-being during initial recovery from the acute impact of surgery, radiotherapy and chemotherapy. As one 45 yr old woman (PT01) treated with chemo-radiotherapy for cervical cancer commented:

"Oh....totally put on hold, I mean I was just trying to survive! Yeh, and the sexual side of me is still put on hold as I'm just trying to emotionally deal with what's happened but I...I...I have got it in my diary [PT smiles and researcher laughs] to deal with that [sex] when I come to it.......and the fact is that I'm fine, I'm fine you know. You know, I'm alive and I'm fit and I'm....yeh, so you know, and I'm always aware that he's [consultant] probably got people dying up there [the in-patient unit where a friend of hers had died of the same disease] you know what I mean? Sex is, come on, forget it! Don't care if you never had sex again...."

[PT01: 45yr old woman 21 months post chemo-radiotherapy for cervical cancer]

Partners often appeared to feel overwhelmed during the initial treatment period and did not consider sexual concerns important when compared to the survival of the person they loved:
"I must admit, I just, I wouldn't say I was dazed, stunned, but I, it, there was so much going on and to be honest with you at that time you are just glad that the one you love has come through it. Really you think well sex don't matter, it doesn't, it's not important at all, you know, because she's here, that's all I've got to worry about, ehm, which is true, I mean absolutely true."

[PTNR03: husband of a 63 yr old woman [PT07] who had an abdomino-perineal resection for rectal cancer]

Women spoke of the need to divert their energies to focusing on coping with the disruption daily radiotherapy had created in their lives and of becoming adept at managing treatment side effects such as fatigue and lymphoedema.

"....I think I would have been more amazed at how can anybody be possibly have been thinking about my sex life when I'm finding it difficult to walk up stairs.....It [sex] would have come very low down my pecking order of recovery.....of priorities, it really would. It was, ehm, it was being able to push the supermarket trolley round, that felt like [an achievement]."

[PT11:59 yr old woman 12 months post surgery / chemo-radiotherapy for cervical cancer]

A number of women experienced treatment late effects that created functional difficulties or permanent changes that required adaptation and acceptance not just from the women but often from other family members too.

"But eh, having, having this operation and now this bag [permanent colostomy] this made me talk about things differently to everybody......because everybody wants to know, because no-one who I know or the family know have got one of these, so 'cause it was....Oh, let me have a look, where's your bag? And even my sister said to me, she said I wouldn't even know you had one, she said. I said no, it's a marvellous thing, but I'm still here to tell the tale. That's the main thing!" [PT07:63 yr old woman 12 months post chemo-radiotherapy and abdomino-perineal resection for rectal cancer]

Adaptation to permanent functional changes appeared to be moderated by feelings of gratitude regarding their survival in light of the threat posed by cancer. This often meant that women were relatively uncomplaining about the nature and extent of treatment late effects they had to tolerate on a day to day basis. Indeed many women took great pains to ensure that I did not misinterpret negative comments about side effects as a criticism of their treatment team.
"Researcher: Is there anything else you would like to add to what we've already talked about?
PT15: No, I don't think so. But I wouldn't like you to feel that I'm criticising my treatment at this hospital.
Researcher: I don't feel that at all.
PT15: I, it's been absolutely wonderful. I don't think I could have had better treatment anywhere."

[PT15: 70 yr old woman 24 months post surgery/radiotherapy for endometrial cancer]

In reaching such a rationalisation and reappraisal of their circumstances it was not uncommon for women to feel that it would be inappropriate to raise concerns about their sexual recovery with medical staff for fear it would be considered ungrateful or inappropriate in light of the fact that the threat of cancer had apparently been averted.

"Researcher: ...As you say the reality of the side effects that you are now left with, is it the bowel side effect is the main one that you think about in terms of it affecting your life?
PT22: No...no not just that I suppose we're not sexually active anymore and that's a problem with me now. Ehm, so yeh, those are the two main issues.
Researcher: Bowels and sexual activity....
PT22: Yeh, but I'm not really sort of going to dwell on it and lose any sleep. I'm here and I'm alive and ehm, I'm really healthy, I eat healthily and ehm, try to take as much exercise as I can, ehm, and just try to give myself a good chance really. Obviously afterwards, you know, six or seven months afterwards you do start to think....well, especially for [husband's name] and what have you, and the need [for sex] would be there for me still. But I was just, yeh, there was just no way that I would contemplate it [attempting intercourse].
I didn't know who to talk to about it, well there isn't anybody and you feel a bit....I would feel ridiculous I think. Ehm, because you're lucky to be alive, I mean why would you think that [sex] would be important at that stage, do you know?" [PT22: 51 yr old woman 26 months post surgery/radiotherapy for cervical cancer]

In addition to the adjustments made by women, it was clear that partners also changed their expectations where there was doubt about the couple's ability to continue with the sexual elements of their relationship.

"My husband loves me a lot, I mean really, he's a super husband and I think partly he didn't want to hurt me obviously and ehm, so I was worried about it [resuming sex] and we talked about it and he said no, it didn't matter, he was just pleased that I was here and we have so much. Because we are really a loving couple, I love him to bits. And, ehm, so it wasn't a problem, it is only a problem that I am thinking for him, but ehm, he, I really genuinely believe he doesn't, he doesn't mind, he just doesn't, I think he's so grateful I am here, actually." [PT16: 56 yr old woman 24 months post surgery/radiotherapy for endometrial cancer]
"But it's kind of strange, I mean I've always been very, we have, the two of us have always been very, I suppose very sexual in that sense, had a long, a long and very pleasant sexual relationship in that sense. But I guess I kind of, how do I see it? I thought well that's it [end of their sex life together]. I mean it's a very stupid thing to say but, you know, she's here and that's it. It worries her more than it worries me."

[PTNR04: husband of PT16]

7.1.1 Changed Life Priorities after Cancer

Women talked readily about how experiencing cancer had led them to reappraise their lives and to consider their current priorities compared to the time before cancer. The need for re-prioritisation was encountered as a process that encompassed a series of re-appraisals during women's recovery from the acute effects of their treatment towards their return to work and other pre-illness activities.

One woman, herself a medical practitioner, with a strong religious faith commented:

"....And always I pray and I say, thank God I have hands and legs. I didn't appreciate my health before because I was too busy, now anything I do I thank God.....thank God I'm in a state that I can wash and clean. I can go down to do my clinic and I thank God I am back, not as normal as before, but I am trying my best and I am OK. When I do a caesarean section, I just manage cases, I feel really very grateful to God."

[PT18: 46 yr old woman 6 months post surgery/radiotherapy for endometrial cancer]

For some women the physical and psychological impact of diagnosis and treatment resulted in a loss of sexual desire and this further reduced any motivation to prioritise sexual adjustment post-treatment, acting as a welcome relief when there were other priorities to attend to:

"I remember feeling a bit upset for a couple of days and kind of like crying about it [sex life], but in relation to everything else that I was feeling it kind of, it didn't stand up there as a big issue for me. In a way it was almost slightly a relief because I didn't even want to have to even think about or cope with having sex. So the fact that I didn't even feel the urge or need for it in any way was almost like taking away the responsibility for having to deal with it, because it just completely, I felt completely numb, there was just no sexual feeling whatsoever." [PT12:42 yr old woman 14 months post chemo-radiotherapy for cervical cancer]

Health professionals caring for these women through treatment and subsequent follow up often bore witness to these shifting priorities as women came to terms with the increasing likelihood of their future survival.
"So that's actually overwhelmed them, that diagnosis and where it [the cancer] is, it has meant that that's all that they think about, that sex has become a very...another issue, it's just not important anymore."

[HCP07: Radiotherapy department staff nurse]

It appeared difficult for health professionals to ascertain the relative importance of treatment induced sexual difficulties to individual women or couples, particularly in the absence of any baseline knowledge about their general and sexual relationship context or any specific enquiry during follow-up about the wider context of women’s changing life priorities as their survival period post-treatment extended (sections 5.3 and 6.3):

“I think that once you’ve finished your treatment then you might start thinking, Oh....what’s going to happen about sex, but when you’re actually having it [treatment], although you do think ‘Oh I hope I’m not going to be totally frigid and hate sex’, but at the same time you’d rather be alive than to worry about sex at that point. So that’s kind of so far ahead you just think, well once I get to that stage then I’ll be happy to deal with it. But before that the thought of sex is just, you’re not even thinking about that, you’re thinking about...hold on a second, am I going to be here for my children? Or how can I, you know, fit this radiotherapy and then go next week and have this....you know, it’s more organisation and worry and stuff like that. You know, before you start thinking about sex that’s one of the, once you get to the stage of recovery you think, Oh, I hope I’m OK!” [PT05: 36 yr old woman 12 months post surgery/chemo-radiotherapy for cervical cancer]

7.2  Relationship Impact

In considering the effect any significant illness or treatment has on a woman’s sexual life it is usually helpful to place that evaluation in the context of her current or previous intimate relationship(s) (Hawton, 1985). Nineteen of the 24 women interviewed for this study were in a heterosexual relationship. Five women were not in a current relationship with two citing the stress of their illness and treatment as the reason for their relationship ending. There were no same sex couples in this study.

The interview schedules for women and their partners (see appendices 15 &16) asked about the impact, if any, the experience of cancer and its treatment had had on the couple’s general and sexual relationship. The specific impact on the woman or couple’s sexual relationship is explored in more detail within the data category Living with a Changed Sexual Life after Cancer (chapter eight) and so this section will focus largely on comments women and their partners made regarding changes in their general relationship as they shared the experience of going through cancer treatment.
Both the women and partners interviewed demonstrated an awareness of the influence a cancer diagnosis had on the couple dynamic, as one partner explained:

"No, it [illness] puts, it puts a strain on the individual, the individual, so obviously puts a strain on the relationship. Ehm, I found it very difficult, particularly initially, to know how to play it. How to be supportive but at the same time not intrusive, it's a, but, I suppose the only advantage of surviving sixty odd years and several relationships is one learns to follow one's intuition." [PTNR05, a gentleman >60 yrs living with PT21, a 54 yr old woman 18 months post chemo-radiotherapy for cervical cancer]

From talking to women and their partners about how their relationship had been affected during treatment and in the early months following its completion there appeared to be three main relationship patterns that emerged:

- Increased emotional closeness and intimacy within an existing supportive relationship with the partner as the principal source of emotional support
- Emotional withdrawal within an existing supportive relationship with the woman choosing to manage her own needs alongside incidental support from her partner
- Increased emotional distancing in a relationship experienced as unsupportive with the woman managing her support needs without her partner

7.2.1 Becoming Closer and Leaning on Him

Women who experienced their relationships as supportive and emotionally close found that the experience of going through cancer treatment often resulted in the couple becoming even closer. As one young woman with cervical cancer who had lost her final pregnancy as a result of starting cancer treatment explained:

"I think it [having cancer] has probably had the effect of bringing us a lot closer together because of the loss of the baby, because we have five children anyway and, ehm, the loss of me not being there perhaps, and I think it, as a family it has actually brought us closer. Although we were a very close family anyway, but I think it has made an appreciation that we don't have endless amounts of guaranteed time, you know, it has made us think...."

[PT05: 36 yr old woman 12 months post surgery/chemo-radiotherapy for cervical cancer]

Other emotionally intimate couples did not perceive there was any change in the relationship dynamic, feeling that the high level of support that naturally occurred in their relationship simply continued, albeit with what may be considered some additional
affection or consideration from the partner in acknowledgement of what these women endured and had to adjust to as a consequence of intensive treatment.

“Researcher: What effect has it [experiencing cancer and its treatment] had on the two of you?
PT07: None really. We are just the same as what we were before. There’s no difference. No difference at all.”

“...We’ve always been a very loving couple, we have you know, we’ve been married forty six years and, we’ve always had a very strong relationship you know, ehm, so I think, I don’t think anything has really changed, you know......It’s true, and that has continued, you know, ehm, maybe, I don’t know, maybe I give her an extra squeeze now and again and tell her she’s wonderful, but.....I, you know, I do my, I do make a point now since the operation in telling her everyday how marvellous she looks, you know.” [PTNR03, married to PT07:63 yr old woman 12 months post chemo-radiotherapy and abdomino-perineal resection for rectal cancer]

For some men the support was predominantly emotional while for others it was more about assisting with practical chores as their partner recovered from the acute treatment effects. As one 74 year old husband explained:

“Ehm but again probably in the earlier days after she had the surgery and all the rest of it, you know, she was more than content to be able to sit down and I just got on with it. So yeh, I mean there have sort of been little adjustments but I mean not because I, I mean I don’t resent it it’s just the way that it’s gone and there are times when I will say, you know, I will wash up, go away, and I’ll shut the kitchen door.” [PTNR02, married to PT10, 68 yr old woman 24 months post pelvic radiotherapy and anterior resection for rectal cancer]

This couple were one of the oldest in the study and had what some might consider quite a traditional division of domestic labour but his wife told in graphic detail of the lengths her husband would go to ensure her comfort as she coped with the acute radiotherapy induced side effects of diarrhoea and moist desquamation.

“I didn’t quite understand what skin breaking down meant, to be honest, so I used to have to ‘up end’ myself every day and [husband’s name] used to have to put all this stuff on me, he’s fantastic, he’s absolutely fantastic......I have an incredibly wonderful husband who was so patient, he still waits on me hand and foot, he’s a fantastic man. But we’ve known each other since we were more or less children,
we grew up together.” [PT10: 68 yr old woman 24 months post radiotherapy / anterior resection for rectal cancer]

For some couples the experience of cancer had resulted in a reappraisal of the nature and amount of time the couple usually spent together with one husband explaining how he and his wife had agreed to alter their family life to spend more time devoted to them as a couple:

“....We spent some time together, it took, we went and took a few days off post treatment, whenever, at the earliest convenience, and we just said so what’s going to change so that we deal with this? And we made a commitment that we, you know, we would do certain things on our own to the point where, you know, the kids are an age now also where they can pretty much look after themselves. Two are away, two are in secondary school and you know when you have four kids the younger two are easier to look after anyway because they don’t have such great dependencies because they have been part of a bigger family. So we made a conscious effort to spend (a) time and (b) do some things, you know, we wanted to do!” [PTNR01: 41-50 yr old man married to PT09, a 50 yr old woman 12 months post chemo-radiotherapy / abdomino-perineal resection for rectal cancer]

For one woman in particular the experience of being diagnosed with cancer had acted as a catalyst to address problems in her existing relationship through counselling and in so doing she had been able to develop a more intimate relationship which had benefits for the couple’s general and sexual relationship.

“PT12: ....our sex life is the same as it was pre the treatment, but because I'm different as a person I feel different about it [the couple’s sex life].
Researcher: Right, in what way are you different?
PT12: There is a stronger connection between the two of us but that's because I've, I've worked at stuff on an emotional level which has impacted on our sexual relationship.
Researcher: And do you think that would have happened anyway? Or do you think the cancer kind of brought it to a head and made you face those things?
PT12: I think that the cancer definitely brought it to a head. It might have, I might have faced it eventually but I think it would have taken a lot longer........But I think the cancer was a catalyst for a lot of things in my life!” [PT12: 42 yr old woman, 14 months post chemo-radiotherapy for cervical cancer]

This woman's account illustrates that a woman's sexual life and adjustment after cancer is often more fully understood within the context of her general relationship. There is frequently a close association between women’s sexual satisfaction and the ability to
experience emotional closeness or intimacy within the couple relationship as PT12’s story shows. Hence when assessing the sexual consequences of pelvic radiotherapy it may be worth considering the inclusion of brief information about the couple context to inform the next steps for a woman’s sexual and emotional recovery and to appreciate to what extent the partner may support or delay this adjustment.

7.2.2 Creating Distance

Some women talked about how going through cancer treatment had led them to emotionally withdraw from their partner, regardless of whether or not the partner was being supportive. This appeared to be a personal coping style whereby the women had a preference to be self-reliant as opposed to looking to their partner for support.

"...I said look, I'm just so awful, you know we spoke two or three times a day but I said, 'Don't come and see me, it's just, I am just a waste, I am just not worth seeing, I, I'm, I don't want to see anybody.....so in a way I could go into my lair and lick my wounds and just hide away until it was over."

[PT23: 58 yr old woman 29 months post chemo-radiotherapy for anal cancer]

"Ehm, well, I think I became terribly sort of selfish and ehm self-centred, I mean I just ignored him basically. I didn't, well I, at that time it was, I wasn't really interested in how [husband's name] felt about anything, ehm, and I very rarely put myself first, you know, I'm a mother of four children sort of thing so I'm way down the pecking order normally. But at that particular time, ehm, I think my way of coping was, you know, I didn't even discuss it with [husband's name] because I really didn't care what he felt about it, if you see what I mean, you understand? So I mean he was very supportive but I kind of shut him out really."

[PT09: 50 yr old woman 12 months post chemo-radiotherapy and abdomino-perineal resection for rectal cancer, married to PTNR01]

This woman’s husband was aware of her shift in focus but seemed to attribute this to the fatigue she had experienced post-treatment.

"PTNR01: The post therapy, her tiredness.
Researcher: Tiredness, yeh.
PTNR01: That was the thing that most impacted her and impacted on our relationship.
Researcher: Right. Can you say a bit more about in what ways did it kind of impact on your relationship do you think?
PTNR01: Eh, she became er, irritable, ehm, she became inwardly focussed."

[PTNR01: 41-50 yr old man married to PT09]
However, what this woman’s partner did not appear aware of was that his wife may also have been avoiding the potential for emotional and thus sexual intimacy as she coped with the acute side effects of chemo-radiotherapy:

"Not at the beginning of radiotherapy but when it just became so uncomfortable and, although he was sort of sympathetic and we could still laugh about the fact that I was, you know, wearing his boxer shorts and things.......to have to see his sort of face going, you know, that looks awful and that looks sore and you know, I did sort of show him, I mean we are very free and easy with each other, but I suppose I just didn’t want him anywhere near me!" [PT09]

While for PT09 withdrawal was a temporary coping strategy associated with acute treatment side effects, for other women their withdrawal was more protracted and appeared to be linked to fear associated with resumption of their sexual relationship.

"PT24: He was very supportive.....he was always ringing to see how I was feeling....I think I, I actually moved into the other bedroom, can’t remember, at some stage I went into the other bedroom because ehm, I was having to go to the toilet all the time and....
Researcher: Just disturbing both of you...
PT24: Yes, he wasn’t getting any sleep so....
Researcher: And when you think about having gone through the radiotherapy and beginning to recover from it, what impact did the experience of going through treatment have on your sexual relationship together would you say?
PT24: Ehm, I think it definitely had an impact quite largely....I was too scared to go near him, ehm, and I probably stayed in the other bedroom for a lot longer than I should have but, ehm, I was really quite frightened because I wasn’t feeling well and ehm, he’s very good and patient, he was marvellous, but, ehm, no i found it very difficult." [PT24: 54 yr old woman 12 months post chemo-radiotherapy and anterior resection of the rectum]

"PT02: I was more distant. Yeh, I don’t know why, I just got more distant, I don’t know, strange.
Researcher: And has it stayed like that or has it gone back to normal?
PT02: No, it has stayed like that.
Researcher: So you still feel a bit distant from him?
PT02: Yes, I don’t know why. I don’t know whether it’s the fault of, how can I put it, ehm, knowing I have had a tumour there, ehm, and knowing it has gone, touchwood. It’s just the thought that maybe having sex could do some damage and bring it back, I don’t know, strange." [PT02: 51 yr old woman, 12 months post chemo-radiotherapy for anal cancer]

This lady (PT02) illustrates how women may hold myths about the relationship between their cancer and sexual activity. If these myths are never voiced to health professionals they can not be appropriately corrected and thus her maintenance of emotional distance to
avoid sexual contact remained a coping strategy. As a consequence this lady continued to ignore sexual approaches made by her partner of 35 years and had come to accept that their relationship had changed to one that was asexual.

"...we had something there, holding hands, but now it's like I walk in front, he walks behind, I don't know what it is, it's like we're sort of, 'cos he's older than me anyway, so it's like father and daughter sort of thing...." [PT02]

7.2.3 Poor partner support and relationship breakdown
While the majority of women who took part in the study reported being in a supportive relationship, a minority of these women experienced poor levels of partner support and couple communication difficulties that were exacerbated by the stress of their illness and treatment. Where the relationship context is one of poor communication, misunderstanding and a lack of emotional support one might expect these women/couples to have greater difficulties negotiating the relationship adjustments necessary to promote sexual recovery after treatment completion.

What became apparent was that if the pre-illness relationship context was one of conflict or one where the woman was the principal source of support for her partner, then when her personal need for emotional support increased the male partner did not appear able to respond to this additional demand on his limited emotional resources.

"PT01: Well he couldn't cope very well, he did his best, he sort of saw me through the treatment with enormous effort and then he collapsed and started [drinking].....he's an ex-alcoholic and drug addict and he just started I think in the last week of treatment....
Researcher: So emotionally he obviously found it very difficult?
PT01: .....He, he found it very difficult and I.....there were obviously fissures in our relationship anyway .........I would guess his inner feelings were he'd always been the one that......I was the strong one and he was the weak one and I guess, really my instinct is that he's like.....'Oh shit, fuck, you know, I can't....you know, god you know......she's gonna be a burden and you know, you know.....what about me? .....I was his emotional nurse and then I needed him and so that was the...." [PT01:45yr old woman 21 months post chemo-radiotherapy for cervical cancer]

There was also evidence that even in relationships the women considered strong and supportive, partners could be so shocked by the diagnosis that they were temporarily unable to offer support because of their own distress at that time.
“I felt I had to be strong for [husband’s name] because he just went into shock.” [PT22: 51 yr old woman, 31 months post surgery / radiotherapy for cervical cancer]

“So I suppose when I finally went to my GP and was diagnosed, well was referred then to ehm, to a specialist and then was diagnosed I was completely shocked, completely and utterly shocked and I suppose that affected our relationship for a while because we were both so shocked and upset by the whole thing.” [PT09: 50 yr old woman 12 months post chemo-radiotherapy and abdomino-perineal resection for rectal cancer]

These findings may be evidence of one of the consequences of clinical staff not exploring the emotional impact of cancer on the woman’s wider relationship. Women may have their usual support mechanisms undermined and find it difficult to access alternative sources of support. PT22 explained how responding to the side effects of treatment caused tension in her relationship and acted as an additional source of stress at a time when she was already feeling unsupported:

“I remember at one stage when I was really poorly and I suppose I’d got up in the night one time and this is one instance when I was really cross with him....and ehm, I was in terrific pain and I was sitting on the loo and it [diarrhoea] was just non-stop and there was bleeding and it was horrible and nobody to turn to and he actually came in the middle of the night and opened the bathroom windows and went back to bed, so obviously it was the smell.....” [PT22:51 yr old woman 31 months post surgery/radiotherapy for cervical cancer]

This woman cried during her interview when she recalled this time and in my field notes I recorded the fact that although this woman’s interview was only 40 minutes duration I spent approximately three hours at this woman’s home as it became clear that she had not felt able to discuss her residual anxieties with her consultant (she was a private patient) since completing her treatment and was unaware of the specialist nursing services available at the cancer centre.

I felt it was important to manage the professional boundaries of my roles as a woman, nurse, researcher and psychosexual therapist and it was at times like this that I found myself having to wear a number of different hats. I recognised there was both a professional and moral imperative to work in partnership with these women, offering support and understanding for their personal circumstances when they were so willing to share difficult experiences with me in the name of research. I viewed the women in my study as partners in a process of mutual discovery as opposed to research subjects from whom my task was simply to extract data. This meant that when emotions were expressed
within interviews, or further discussion was needed, I sought to act in a way that was consistent with the principles underpinning feminist ethnography while being mindful that my interactions with these women was both boundaried and time limited and so I always had to act with the women's future well-being in mind.

One of the youngest women in the study talked about how she had argued with her partner as he did not believe her when she tried to explain that her loss of interest in sex was related to her treatment. This woman also feigned illness in order to avoid sexual contact with her partner because she had no sexual desire following her pelvic radiotherapy and did not feel her partner always understood this when he approached her for sex.

"Sometimes we argue. Yeh, because sometimes I will say I'm sick, sometimes I will say I don't feel well, trying just to...

Researcher: To put him off?

PT13: To put him off, yeh. But then he realises that, he's started realising that now. Sometimes we argue about it... sometimes he is very understanding. He knows what I've gone through, why I'm being like that. But sometimes he just flips and says, 'Oh maybe you've got a boyfriend!'

[PT13: 32 yr old woman 16 months post radiotherapy for cervical cancer]

Once more it was hard for me to hear that this woman felt there was nobody at the cancer centre that she could talk to about her relationship difficulties and so she had to manage this difficult dynamic with her partner alone. She had been started on hormone replacement therapy by her GP to improve her absence of sexual interest, and had placed a great deal of hope in the HRT leading to some improvement, but after 12 months of treatment had seen no change in this aspect of her relationship.

"Yeh, I wouldn't know who to tell about what's going on. It's really affecting my relationship a lot because he thinks, he suspected that I've got a boyfriend, I've got somebody. Sometimes he's understanding, sometimes he knows that Oh well it could be that [the treatment], because sometimes I go on the internet and ask him to read the side effects, because everything says that it could, you could lose your libido and all that. But men are men!"

[PT13]

After this woman's interview had been concluded she confided that one of the reasons she had agreed to take part in the study was in the hope of being given some help regarding her sexual and relationship difficulties. So we discussed sources of specialist counselling and I encouraged her to request referral to a specialist menopause clinic to try to optimise
her hormone replacement therapy. This woman had not requested nor received any assistance regarding these issues from her treatment team despite attending regular follow-up appointments over a 16 month period.

Five of the women and one health professional spoke about the potential for relationships to break down as a direct result of going through cancer treatment, with actual relationship breakdown occurring for two of the study participants (PT01 and PT04). There was no evidence in this study that health professionals were aware of these relationship consequences as the woman’s relationship context was not enquired about in follow-up consultations. As previously mentioned, it appeared that the additional stress of facing cancer had been too much for an already fragile relationship to withstand and so the illness had been a catalyst for change. As one woman who had recently split from her partner explained to me:

“And in my mind I’m thinking to myself, I don’t need all this, he had a lot of agro as well which was half, it was a lot of his fault, agro, and I said ‘Look, I’m sorry [partner’s name] but I’ve got my family and I said I’m sorry I can’t take on all our troubles, I don’t want worry. It’s the worst thing for cancer is stress and I don’t want that. I said I think you best to….eh, leave and it was lucky we weren’t living together because I could never live with another man, Isabel, not because of the cancer, because I’m too free!”

[PT04: 64 yr old woman, 8 months post chemo-radiotherapy for cervical cancer]

Other women stayed within their relationship but were aware that the experience of going through cancer treatment had caused relationship strain which had been an additional source of psychological stress that they wished they could have avoided.

“I mean it is quite possible maybe that at some point when my partner, like, we no longer lived together and I felt there might have been possibilities at one point, there were times I tried to end the relationship during treatment, ehm, because I, I just didn’t want to deal with, with stuff at all. There were times when I even talked about it in counselling. Where I was too frustrated with some of the other stuff that was going on in our relationship I just didn’t want to have to deal with it on top of everything else. So there were lots of times when our relationship could have ended and it didn’t for lots of different reasons.”  [PT12: 42 yr old woman, 14 months post chemo-radiotherapy for cervical cancer]

This woman had made a self-referral to a local cancer help centre and received 12 months of counselling which she had completed two months before her interview with me took place. She was a social worker by professional background and had expressed concern
about the apparent lack of attention devoted to the psychological impact of cancer and subsequent emotional support needs by her treatment team at the cancer centre.

What was clear from the interview transcripts was how central the women's intimate relationship was to their sense of emotional support at times of high psychological stress and yet this aspect of these women's lives was not actively explored or engaged with as part of their medical management within the clinic, as discussed previously in section 6.3. The exclusion of interpersonal elements of women's sexuality is congruent with the construction of female sexuality after cancer treatment in what may be regarded as narrow biomedical or essentialist terms, as discussed further in sections 11.2 and 11.3.1.

7.3 Being Sexual for Him: the heteronormativity of female sexuality

As mentioned previously, five out of the twenty four women who took part in this study were not in a sexual relationship at the time of their interview. I had made a conscious decision at the time of establishing inclusion and exclusion criteria relevant to this study to be inclusive in reaching a definition of female sexuality and sexual expression stating the sample would include: "Women who have engaged in some form of sexual expression within 12 months of their treatment commencement" (see table 3.3 for study inclusion criteria). My rationale for including women who were not in a current sexual relationship in the study was twofold:

- As a woman and psychosexual therapist I endeavour to define female sexuality and sexual expression to be inclusive of but not solely determined by the presence of a sexual partner of either gender
- Women who are not in a sexual relationship at the time of their diagnosis and / or treatment may have additional sexual and relationship concerns that would require adequate assessment and support within clinical service provision and are thus an important group to include in any sampling strategy

An analysis of the 17 women who had sent back a refusal response following their invitation to participate revealed that of the seven women who gave a reason for not wishing to participate in the study, six of them cited not being sexually active with a male partner for a number of years as the reason for non-participation. Interpretation of extracts from written comments suggested
that these women principally defined “sexual activity” as sexual intercourse with a male partner as opposed to non-coital or self-stimulation forms of sexual expression:

*PTRef05*: I received your information today and have no objection to taking part however I have not been sexually active for some years and this is not related to my treatment. Although married my husband and I live separate lives and this, I think, excludes me from this study. Good Luck. [58 year old woman 18 months post surgery/chemo-radiation for anal cancer]

*PTRef013*: At 75 years of age and being a widow for 20 years I cannot but feel my input would be less than useful. [12 months post surgery / pelvic radiotherapy for endometrial cancer]

*PTRef12*: I would be only too pleased to help you in any way I could but as I have not had intercourse with my husband for 10 years, having the problems I have now, of course, do not affect this. [66 year old woman 26 months post surgery/pelvic radiotherapy for endometrial cancer]

Three of the seven women who refused to participate phoned to discuss their reason with the researcher and all expressed interest in and support for the topic of the study but again indicated that they had little to offer due to what they considered to be protracted sexual inactivity. One woman (PTRef09) had a lengthy discussion about her lack of sexual interest following a natural menopause at the age of 54. She was in a heterosexual relationship at that time but intimated that as her male “friend” had erectile dysfunction they were both happy with an “asexual friendship” and continued to be so. Despite her personal circumstances she volunteered that she had never been asked about her sexual recovery during follow-up consultations and would have been happy to have answered interview questions related to the lack of communication with health care professionals about sexual issues which she felt was an important aspect of her care (PTRef09: 59 year old divorced woman 12 months post chemo-radiation / surgery for rectal cancer).

The data from women who refused to participate in the study illustrates the complexity of promoting inclusiveness and diversity of sexual lifestyles in sexual health research sampling where participation is, by its very nature, voluntary. However such sampling outcomes reinforce the perception that female sexuality is largely invisible out with the context of heteronormativity and heterosexual relationships.

Of the five women who were not in a sexual relationship at the time of their interview, three spoke of masturbation as a source of sexual expression and satisfaction that they engaged in:
"PT17: Yes, well the thing is I do, I do use a dildo and masturbate in any case so it's not very much different using that, the dilators.

Researcher: So is the dildo a vibrator?
PT17: No, it's just a straight dildo.

Researcher: And in terms of masturbation is that something you would tend to do on a fairly regular basis?
PT17: Ehm, it varies, but yes, ehm, certainly sort of once a fortnight anyway, if not once a week." [PT17: 67 year old woman, no current partner, 15 months post chemo-radiotherapy for bladder cancer]

Four women who had a current partner also engaged in masturbation with or without their partner present. This would suggest that women may be engaged in a more diverse range of sexual behaviours but this information would be unlikely to be elicited within a clinical context and is infrequently sought in studies of sexual dysfunction in oncology as reviewed in chapter two.

All the women who took part in the study were currently or had been in a heterosexual relationship and there was no evidence of any woman having experienced a same sex relationship prior to their inclusion in this research. These women predominantly viewed their sexuality and sexual life within the context of their partner relationship both prior to and following their cancer treatment. This led them to express concern not only regarding their own sexual wants and fears but to voice regret at not being able to offer their partner an outlet for sexual expression as they had done before their illness.

A number of the women spoke about the importance of being able to be sexual after cancer treatment for the sake of their relationship or to fulfil their partner's sexual interest as opposed to emanating from their own desire for sexual intercourse. One of the outpatient staff nurses (HCP15: female, aged 51-60 yrs) felt that some women viewed having sexual intercourse with their partner as a type of "duty" they wanted to fulfil and that this prompted them to address the topic of sexuality with her as a health care professional:

"...[they say] but I am a wife and a woman and I need to, you know, fulfil some kind of duty or whatever, it's that maybe from yourself and they start talking to you."

[HCP15]

The ages of women expressing such views ranged from 32 years of age to 68 years but there did not appear to be any clear generational differences regarding the extent to which
women would engage in sexual intercourse even though they felt no desire for sexual expression themselves.

"Researcher: Was that because you felt your partner needed that reassurance or.....

PT12: Partly, yeh, yeh, yeh. And he'd gone so long without that [intercourse], you know, ehm, that part of me I guess felt a bit, maybe a bit guilty, a bit kind of responsible for meeting his needs, ehm, even though for me it wasn't that important at that time. Ehm, there were times when I did say no, ehm, and that I, so I, I tried, I think there were times when I did go along with having sexual intercourse even though I wasn't quite sure, but I kind of felt maybe I had to push myself to do it in a way, because it was like if I don't start to push myself in some respects then I'm maybe never going to a, I'm never going to know how I do feel when it happens."

[PT12: 42 yr old woman, 14 months post chemo-radiotherapy for cervical cancer]

"Researcher: And how would you compare it now to say before your illness, your interest in sex? Would you say it's back to normal?

PT10: It's probably less but if... we've been a couple for so long. If I'm really tired I will say no. Occasionally I initiate it, but not very often. Ehm, I could probably, Oh don't tell him, I could probably live without it but he still wants it, so he gets it, you know. And, once I get going then I'm alright but sometimes, to be honest, I'd rather read my book." [PT10: 68 yr old woman 24 months post chemo-radiotherapy / surgery for rectal cancer married to PTNR02].

Interestingly this woman's husband also alluded to the possibility that couples may not share the desire for sex at any given time but that partners may be prepared to engage in sexual intercourse even if they personally did not enjoy the experience on that occasion:

"I mean most couples must have some sort of sexual relationship, however good or bad, ehm, and even if, even if one doesn't necessarily enjoy it they will probably do it [have sexual intercourse] for the benefit of the partner."

[PTNR02: 61-70 year old man married to PT10]

There was a sense that many of the women were grateful for the understanding and patience shown to them where their partner had adjusted to the reduced frequency of sexual contact that had occurred within their relationship as a consequence of cancer treatment and was not making unreasonable sexual demands. This led to some women feeling they should engage in sexual intercourse to show appreciation of their partner's consideration.

"I think there was slightly less [sexual] interest there. But I didn't give in to that because it wasn't fair to him. He was being so good to me ehm, but it wasn't
something, I didn't feel put off by it at all, there just wasn't as much interest as before but once we started maybe it was, it was OK.”

[PT19: 62 year old woman 17 months post surgery/radiotherapy for endometrial cancer]

“But I just tried my best [to be sexual]. Mainly because I knew that, you know, he was still sexually active even if I wasn't and when somebody's been so good and kind to you anyway you want to look after them as well. But oh, it was definitely a very hard time and he never ever put any pressure on me, he was so good. Because I used to start feeling guilty when it was getting up to about a month and I thought, aw, so I used to try to look after him somewhere about every, once a month, you know, that wasn't....we always previously to that it was at least once a week.” [PT24: 54 year old woman 12 months post chemo-radiation / surgery for rectal cancer]

Some women no longer felt they wanted to engage in penetrative intercourse but would either adopt non-coital forms of sexual expression to give sexual pleasure to their partner or would engage in intercourse at a reduced frequency because they knew their partner gained sexual satisfaction from intercourse.

“We'll just have a cuddle and whatever we've got to do for him and then that's it really. So it has made a difference definitely to me, I've gone completely the other way, there's still a need there, you know, I like to be loved and I like to feel close to him, and he still needs that as well, ehm, but we've, we just sort something else for [husband's name] really.

Researcher: What sort of ways can you use now to express yourself sexually between the two of you?

PT22: Well I, I don't feel I want ehm any penetration at all now. I will on occasions to be fair to [husband's name] and you know we use gel or Sylk, like…” [PT22: 51 year old woman 31 months post surgery/radiotherapy for cervical cancer]

The specific sexual adjustments women and their partners made following cancer treatment are discussed in more detail within chapter eight: Living with a Changed Sexual Life after Cancer.

Not all partners were able to adjust to substantial changes in the couple’s sexual life. One younger woman found her partner was not always understanding about her total loss of sexual interest following chemo-radiotherapy for cervical cancer and spoke of having to endure the pain associated with intercourse while hoping that penetrative sexual contact would be brief:

“PT13: Yes, the loss of interest, the discomfort and also my, my moods are very unpredictable. Some days I'm fine, some days I'm just too low to talk or anything, yeh.
Researcher: Yeh, is it more painful when you are having sex when your mood is also low or not?
PT13: Yeh
Researcher: So that makes it worse actually?
PT13: Yeh. It would be like somebody’s forcing you. But now sometimes, it’s just like, it’s in my mind and I am like ‘Can’t you just finish and leave me?’

As can be seen from my questioning I was concerned that in addition to a hormonal explanation (radiation induced menopause and vaginal changes) for this woman’s lack of sexual desire and dyspareunia she may also have been experiencing depressed mood due to her illness and the apparent lack of consistent emotional support from her partner. This extract also provides an example of objectification ("…It would be like somebody’s forcing you"…) in her use of language that appeared to serve the purpose of creating distance between her comments and her partner as the cause of her sexual pain.

7.3.1 The asexual older woman

Sexual expression is often viewed as a preserve of the young as exemplified by the literature reviewed in chapter two. In the reality of people’s personal relationships such stereotypes are frequently inaccurate and it is often difficult to determine at what age sexual expression ceases to be an aspect of someone’s identity, particularly where it forms a core component of that person’s adult life. However, as discussed previously, older age is often viewed as time of sexual decline and certainly epidemiological evidence suggests that the prevalence of sexual difficulties increases with age (DeRogatis & Burnett, 2008).

As can be seen from section 4.2 the ages of women who participated in this study ranged from 31 to 81 years of age in the observation data with 46% (n=32) of women in observed consultations under 60 years of age and 54% (n=37) of women over the age of 60 years. In the interview data the women’s ages ranged from 32 to 72 years, with 67% (n=16) of women under 60 years of age and 33% (n=8) of the women over 60 years of age, a younger sample of women than those seen in the follow-up clinic overall.

As the twenty four women who took part in this study all volunteered to discuss their sexual recovery following cancer treatment it may seem reasonable to assume that they considered their sexuality an important aspect of their lives and may therefore represent a group of women who hold more positive views regarding female sexuality than those women who refused to participate.
Analysis of the participant observation data (section 5.3.1) revealed a statistically significant difference (at the 1% level) between the two age categories of women, with older women (>60 years of age) less likely to have discussions about sexual issues than those aged 60 years or younger. Analysis of the interview data also revealed that the majority of health professionals and some of the women themselves felt that older age led to assumptions being made about both the likelihood that a woman was still sexually active and the extent to which she would be interested in discussing the impact of cancer treatment on her sexual relationship with health care professionals.

Sixteen out of 20 of health professionals interviewed considered the age of the woman in deciding whether or not to raise the topic of sexual concerns with them, with only one health professional (gynae-oncology CNS) stating she considered the age of the woman irrelevant in shaping her communication about sexual issues. The likelihood that practitioners would view older women as being sexually inactive or asexual did not appear to be influenced by the age or gender of the health professional. This was the dominant construction of female sexuality in later life in this study.

It was evident from analysis of the health professional interview transcripts that as a result of this collective construction of female sexuality in later life, the majority of practitioners found it more difficult to talk about sexual concerns with older women either because they assumed the women would be embarrassed or have a more conservative attitude towards sex and therefore find discussion awkward.

“But I don’t actually ask them straight…so how is your sex life? Yeh, because older people are more prudish….”
[HCP15: 51-60 yr old female outpatient department staff nurse]

“HCP01: If it’s a really old person I’m not going to ask. Because they are more likely to be embarrassed plus I always think that old people don’t have sex [laughs as she says this] so therefore I won’t ask.
Researcher: And how old is “old”?
HCP01: Well as I’m getting older it’s [patient age category] getting older [both laugh]. Well….probably 70! Yeh….No I’d probably say 70 roughly and also it depends on the person, doesn’t it? If they look, some people look much younger than they are and you look at them and think….maybe you are!
Researcher: So age is obviously a factor
HCP01: Age is a major factor whether I’ll ask or not and also I suppose how chatty they are as well.”
[HCP01: 30-40 yr old female specialist registrar]

Health care professionals differed in their views about how “old” was too old to be considered sexually active but the majority felt that this applied largely to women over 70 years of age. The
likelihood of a woman being currently sexually active was consistently regarded as a criterion for
discussing sexual issues, although some practitioners found it difficult to judge whether or not
women aged in their sixties were sexually active:

“But I mean I class old as over seventy, from a sort of, if they’re sexually active point of
view. Eh, sixty year olds I wouldn’t ehm, sometimes they actually say Oh I’m not, you
know, I’m not sexually active, but they’ll volunteer that. Eh, so it’s the sixty to seventy
age group that could be the grey area for whether you’d spontaneously ask a question
or not.” [HCP06: <30 yrs female specialist registrar]

“HCP02: I don’t think we talk enough about psychosexual issues in general, eh, we tend
to assume that older ladies don’t have sex eh....
Researcher: How old is older?
HCP02: Well, you know, sort of women in their sixties and seventies!”
[HCP02: 51-60 yrs male consultant clinical oncologist]

In practitioners reaching a decision about whether or not to raise sexual concerns during follow-
up consultations the woman’s age was often considered in conjunction with assumptions about
evidence of the presence and nature of any intimate partnership. Hence, older women without a
current partner would be highly unlikely to receive any information regarding their sexual
recovery from health professionals.

“I would probably judge whether I thought they were old or not, whether to mention sex,
especially if they’re post-menopausal, obviously post-menopausal. If you’ve got an 80
year old or something then I probably wouldn’t unless they came with a young husband
and well, maybe you use your common sense because I think a lot of elderly people
would actually probably take offence to you saying it.”
[HCP01: 30-40 yr old female specialist registrar]

In openly expressing their personal views to me about their attitude towards female sexuality
some of the participants acknowledged disquiet at the way in which their everyday practice was
shaped by a stereotypical view of female sexuality in later life.

“Ehm, I suppose to be honest with you I think it probably is you know, the main factor is
if I....it’s really awful, I think the main factor is if I see some little old lady that’s come in
here, is obviously, doesn’t come with, because most people come with a partner. If I see
some woman in her seventies who comes in on her own, without a partner and I have to
say, you sort of, I think that’s.....but I actually think that’s wrong, I actually think my
practice that’s probably wrong...” [HCP05: 31-40 yr old male specialist registrar]

This doctor reflected later in his interview that he felt his “personal system” in deciding with
whom he needed to discuss sexual concerns worked most of the time but he remained
concerned that there may always be an exception to the stereotype and that this would then lead to an omission in the woman's management:

"HCP05: You see I think my personal system sort of, it works for me and it feels OK. My concern is that, you know, there's a sprightly eighty year old that's sexually active and she's too scared to talk about it. I look at her and think....
Researcher: She's too elderly?
HCP05: You know, and she's one of these eighty year olds that's got a boyfriend you know, it always surprises me and you say are you married? And they go....I saw a lady a few weeks ago, she goes Oh no, but I've got two boyfriends, she said, you know, and I'm slightly concerned that we may, that there's, I don't think a huge amount of patients...."

This transcript extract is also interesting in that it introduces the concept of an older woman being “sprightly” as an indicator of her sexuality whereas undoubtedly women who appeared to be physically frail were not viewed in the same way. This is addressed in more detail within chapter nine: “Talking Sex in the Clinic when physical frailty due to co-morbid conditions or progressive disease frequently acted as a barrier to the discussion of sexual concerns within follow-up consultations.

Nurses and radiographers also expressed ageist and heteronormative assumptions about women they were seeing with regards to whether or not they felt it appropriate to offer feminine care advice. One colorectal CNS remarked on how she would challenge her radiotherapy department colleagues if they had omitted to offer a woman vaginal dilators on the basis of a woman's age:

"HCP10: I've had both radiotherapy staff nurses say to me ehm, we haven't addressed fem care because they are old. What do you want to do? Ehm and the assumption is they don't have a sexual life.
Researcher: How old is old, generally?
HCP10: Well, biologically old, I just don't know that we should make that assessment of a patient, ehm, you should just talk to a patient. If they say I don't want [dilators] it's not an issue, it's a different thing.....But I don't think that we should make an assessment on age because they are older or ehm, you know, I always said to them the only reason you wouldn't give feminine care advice is if they've got a gynaecological problem, then don't offer them dilators and things without checking with the medical, if there's a medical reason why they shouldn't."

[HCP10: 41-50 yr old female clinical nurse specialist in gastro-intestinal cancer]

A therapy radiographer also commented on how practitioners managed their reactions to the prospect of discussing sex and the use of vaginal dilators with older women:
"Talking about the effects on their vagina and the skin around the groin and perineum I think depends on the radiographer who's doing the chat and I think probably the older ones are a bit more relaxed about it because you just don't talk about sex with people....maybe with people your own age group, but to talk to somebody in your mother's age group is just, EEK! It's something you definitely have to put on your professional façade for that one." [HCP17: 41-50 yr old female therapy radiographer]

A female specialist registrar (HCP13, aged 30 - 40 yrs) working with women treated for gynaecological malignancy at the time of her interview commented on the reasons why she felt sexual issues were less likely to be raised by women than by the male patients with prostate cancer she had managed in her previous post:

"Researcher: I mean have you any views as to why you think women are more reticent to raise their sexual function with us?
HCP13: I'm not, I'm not sure I mean maybe it's my own perception that I think maybe it's less important for women. I don't know.
Researcher: It's certainly different, I agree.
HCP13: Yes. And ehm it's perhaps still the, yeh, preconception that women are not, you know, allowed to have a fulfilled sexual life or that they are not allowed to talk about it ehm similar to men. And, ehm, perhaps even that you know we think once their fertile period is over, once they've had their children it's not so important for them anymore and often our patients are you know, older than forty, fifty." [HCP13]

This health professional was one of the few who made an explicit link between a woman's sexuality and her reproductive capacity, both of which are adversely affected by cancer therapy particularly in women receiving treatment for a pelvic malignancy. This specialist registrar also alluded to the social construction of female sexuality whereby women are not expected to talk about their sexuality in the ways that men do both in a social and medical context nor is it expected that they will seek fulfilment in and value this aspect of their human experience in the same way that men are seen to do. While this individual's construction of female sexuality is clearly influenced by social, religious and generational attitudes it is interesting how pervasive these personal views are in shaping the way in which we view the sexuality of other women, particularly those older than ourselves.

The influence of health professional age on the view of older women's sexuality was alluded to by HCP01 and is also supported by HCP14, a male specialist registrar (aged 30-40) working with women treated for lower gastro-intestinal malignancies:

"If you see, you know, if you see someone in their sixties er you and you're in your thirties, you sort of think well, is their sex life, is it going to be that important, do I need to sort of mention it?" [HCP14: 30-40 yr old male specialist registrar]
As well as holding views about the sexuality of older women and the impact these may have had on practitioner’s ability to broach the topic of sexual morbidity in consultations a number of the health professionals interviewed spoke about the expectations of older women regarding the doctor’s role in the discussion of what was seen to be a “personal issue”:

“I think that you, particularly older patients still have certain expectations of that authoritarian relationship and probably don’t want to talk about the things that they feel are rather too personal and rather too close to them.”

[HCP18: 41-50 yr old female consultant clinical oncologist]

“Yes, I think I tend to let patients decide what they want to ask me about. And I think for elderly women it’s usually less of an issue. So certainly in my practice elderly patients discuss it much less than the younger ones.”

[HCP20: >60 yr old female consultant clinical oncologist]

Women’s beliefs about the role of their doctors in discussing treatment related sexual concerns are explored in more detail in section 9.1.

Only six of the women interviewed for the study commented that they thought their age made a difference to the way they viewed their own sexuality or, more commonly, felt that health professionals may have considered them too old to be interested in discussing sexual changes after cancer treatment.

One participant (PT03) commented on the way women are portrayed in the media and how she felt that post-menopausal women were no longer viewed as sexual beings as a result of this life transition.

“I work in the movie industry and I’m afraid... oh we deal with this and we’ve done events and we’ve got things you are working on about portrayal of women on the screen. Once you hit the menopause you are no longer a sexual being, you become asexual. So women have enough to cope with at that age anyway without that being further eroded by the feeling that, well you are not going to have a sex life anyway because you don’t have any sex organs left!”

[PT03: 55 year old woman, 8 months post surgery/radiotherapy for endometrial cancer]

Another woman recounted a recent experience when she attended an Ann Summers party and was struck by the generational differences in the women at the party regarding their comfort with talking about sexual matters in a very open manner compared to how she felt about sex being something to be kept personal or private:
"To give you an example I went to an Ann Summers party a couple of years back ...and it wasn't the first one I had been to, I used to go to them years ago and everybody had scribbled their thing [order] in secret and it was all done under the table. Anyway, a couple of years ago I've gone to a friend, she was an ex-girlfriend of my son's so the generation was younger. And they were all very open, all very above board, this is what I've tried and this is what I think is good....I'm going to order this....and I'm thinking My God that was a bit different to what it was a few years ago. So the younger people seem to be able to be more up-front about it [sex]. But whether it's just me, I don't know, my generation thinks Oooh, I don't want anybody to know really. It's a very personal thing and I probably wouldn't admit to it, so it's difficult, it's difficult." 

[PT08: 58 year old woman, 6 months post chemo-radiotherapy for anal cancer]

Although this participant was intimating her discomfort about talking about sex in a public context, during her interview we had been laughing together about the fact that in the absence of a current partner this lady had been using a vibrator instead of the size 1 and 2 vaginal dilators given to her by the radiotherapy nurse because she considered them too small. This illustrates the point that one should not make assumptions that women who consider their sexuality as a private and personal matter are not sexually expressive or experimental within their own sphere of comfort.

One of the women wondered if the health professionals she encountered during follow up viewed her and her husband as an older couple (in their late fifties) and that this might explain why she had never been asked about her sexual well-being after treatment completion:

"PT11: And again I suppose part of me would think that's an age thing. If I'd been thirty five would it have been seen as a [priority], or if it had been a new relationship, or we just got married or something. Because I suppose we were seen as a cosy old couple..... Researcher: I'd say you're not old in my eyes. 
PT11: No. I'm probably not really, no! Researcher: 59's not really very old."

[PT11: 59 year old woman, 12 months post surgery/chemo-radiotherapy for cervical cancer]

This woman's transcript extract is interesting because it sheds light on beliefs she holds that a woman's ability to be sexual is more important at certain times and in certain contexts than in others. For example, a woman's sexuality may be more important when she is younger, newly married or in a new relationship than when she is in a more enduring relationship such as this woman's marriage. This woman had not yet resumed sexual intercourse with her husband due to a changed body image associated with the numerous treatment late effects she was experiencing including lower limb lymphoedema, fatigue and some bowel disruption.
One of the older women in the study (PT15) also rationalised that the reason her treatment team had never mentioned her sexual recovery during follow-up was because she was considered by them to be too old to be sexually active:

"PT15: No-one ever asked.
Researcher: Why do you think that might be?
PT15: I don't know. Perhaps they didn't think it....perhaps they thought I was too old?
(Laughter from participant and researcher)
Researcher: So you'd have been what, you'd have been 68 then, I think.
PT15: Yes, yes. The only person who really discussed it with me was my GP."

[PT15: 70 year old woman 24 months post surgery/radiotherapy for endometrial cancer]

This woman had, however, felt able to ask her GP about the dyspareunia she was experiencing when she consulted him about her treatment induced diarrhoea.

While these women's extracts all refer to assumptions being made about older age leading to reduced or absent sexual well-being, one of the participants expressed her concern that she was too young to accept loss of sexual desire at the age of only fifty-four.

"Ehm and I did see one of the doctors and she was very understanding and it was worrying me because I thought, well I was....what was I?, 53 or 54 at the time and I thought it was too young really to lose complete libido at all, you know that you've just got no sexual desires....." [PT24: 54 year old woman, 12 months post chemo-radiotherapy/surgery for rectal cancer]

7.4 Vagina Monologues

An important insight into the social construction of female sexuality in this study relates to the ways in which women's bodies, or more specifically women's vaginas were constructed or defined as (de)sexualised and diseased body parts in the context of pelvic cancer and its treatment. As discussed previously in section 7.3, female sexuality in this study was defined in heteronormative terms, being largely invisible outside the relationship context. There was a sense that female sexuality was viewed by health professionals and the women themselves as receptive and preferably responsive to sexual approaches initiated by the male partner.

Within the clinic heteronormativity manifests itself as a belief system that values the woman's capacity to be sexually receptive through maintaining a patent vagina that permits penile penetration without adverse effects. Yet in the context of cancer and its treatment the woman's vagina has become a source of disease, fear, pain, discharge, abnormal bleeding,
instrumentation and disease surveillance. This section explores the different ways in which study participants explored and discussed the vagina as a problematic part of the woman's body that required surveillance and management in order to reduce threat and promote well-being.

7.4.1 Intimate Examinations

Vaginal examinations were considered a "routine" component of women's visits to the gynaecology follow-up clinic and, as discussed in chapter six, often held significant meaning for the women in that they were seen as an important contributor to the overall role of the clinic in disease surveillance.

However, some study participants viewed this particular clinical examination as particularly intimate or embarrassing for women and thus for practitioners, often necessitating specific rituals to manage boundaries and thus reduce the likelihood of distress or offence.

"Well I tell all the juniors to feel the neck first because I do think it is, I find it, I would find it quite an assault for somebody to dive straight into my genitals, so I would say, you know, in my career I've found nodes up there that weren't expected probably no more than half a dozen times in the last twenty-five, thirty years but I have found that, but the main thing that it's a way of touching the patients without immediately, you know, whipping their skirt up and I think, ehm, you get an idea then if somebody hits the roof when you touch their neck...."

[HCP02: Male consultant clinical oncologist]

Even though partitions within the clinic room environment did not require him to do so, this consultant chose to leave the clinic room while women removed their underclothes to prepare for vaginal examination and did so again when women were getting dressed following the examination in order to manage the boundaries between the verbal consultation and physical examination.

Rituals of boundary management may be particularly relevant where the practitioner undertaking the vaginal examination is male, for as this female clinical nurse specialist explained:

"Researcher: Does your gender help, you know, the fact that you're a heterosexual female, as it were?

HCP09: I don't know whether it is actually just how comfortable you are and how you perceive things and how familiar you are [with performing vaginal examination], you know, I don't see it as any different to any other examination. You know, you still have the woman there but you know that's just part and parcel of what you're doing, it's no different to anything else that you may do. Other than the fact that you've got to be aware for that woman, obviously, this is much more, ehm, intimate than anything else. But I don't know whether you should go too far down making them think this is something special." [HCP09: Female clinical nurse specialist in gynaecology]
Although this CNS in gynae-oncology was aware that she considered the vaginal examination entirely routine she acknowledged that for the woman this examination was rarely without some degree of physical or emotional discomfort. However, for her it was important to strike the balance between acknowledging this sensitivity while not placing excessive emphasis on the vaginal examination as being distinct from any other type of intrusive procedure associated with pelvic cancer treatment.

Some of the health professionals explained how they would use the findings from vaginal examination as a prompt to ask about a woman’s use of vaginal dilators or to enquire about whether or not she had resumed sexual intercourse post-treatment.

“Researcher: And is the likes of vaginal examination a routine part of your assessment in terms of the physical signs you are looking for?
HCP18: Yes. I mean usually it would be an assessment for recurrent disease in any event. Eh, but it’s also an indication about sexual function as well so eh, clearly if someone’s got vaginal stenosis and some of the elderly patients have, then eh, I would be watching out for that or asking about and that might prompt questions about sexual function.”

[HCP18: Female consultant clinical oncologist]

“Yeh, I think if I noticed a lot of telangiectasia I would normally ask them about whether or not, first of all, they were using the dilators and secondly whether they have resumed sexual intercourse and whether it’s comfortable or did they have any particular concerns.”

[HCP19: Female consultant clinical oncologist]

There did not appear to be any gender difference in relation to whether or not health professionals would use findings from vaginal examination to prompt discussion of sexual implications, it was more a personal communication strategy. The development of specific communication strategies used by health professionals to overcome the difficulties of broaching sexual concerns in the clinic is addressed in more detail in section 9.3.

Both of these transcript extracts (HCP 18 & 19) are from research site B and so there are no linked examples where the perspective of a health professional is contradicted by patient’s transcripts as patient participants were solely recruited from research site A.

Despite a number of health professionals suggesting that findings from clinical examination of a woman’s vagina frequently led to the discussion of sexual issues, a number of the women contradicted this assertion in recalling their personal experience of the follow-up clinic.

“And when [consultant’s name] does the internal he, he sort of has a look and says everything’s fine and nothing is collapsing and from that point of view, but not from a sexual one, no.” [PT11: 59 year old woman 12 months post surgery/chemo-radiotherapy for cervical cancer]
“Ehm again very much on the physical side. Ehm, you know, how are you, did an internal to make sure the healing process was, ehm, had taken place, but again nothing on the sexual side. I thought to myself why am I bothering to come back here every three months if all I am going to get is ‘how are you?’ and have an internal!”

[PT14: 63 year old woman 4 months post surgery/radiotherapy for endometrial cancer]

This latter participant (PT14) had commented on her disappointment at the dominant emphasis placed on her physical recovery within consultations when she would have preferred some attention being given to her emotional and sexual well-being.

7.4.2 Invisible Anatomy
There appears to be a paradox in the ways treatment or illness induced vaginal changes is viewed from a service delivery, health professional and individual woman's perspective. In delivering follow-up to women treated with pelvic radiotherapy the vagina is routinely subjected to intense surveillance in the gynae-oncology clinics while in the gastrointestinal clinics the vagina was usually absent as a focus for clinical examination. This may be explained by differing medical priorities from considering the vagina as a dominant site of disease surveillance to one where the vagina is principally a site of treatment toxicity. Thus, as discussed in chapter six, in the absence of problematic vaginal symptoms among women treated for anal or rectal malignancies, the vagina remained invisible as a site of treatment induced changes in the women's bodies.

“Even though you are irradiating pretty much the same tissues it [vaginal toxicity] never comes up. I've never heard it discussed, you know, all those GI, all those rectums and all those, you know. And although impotence comes up, even in urology, about the women, never heard it, never heard it. And actually, I'll be honest, I'll stick my hand up in the air you never, I've never really thought about it.”

[HCP05: Male specialist registrar]

The vagina was invisible to health professionals and women with rectal, anal or bladder malignancies who were less likely to associate treatment for these tumours with the likelihood of vaginal side effects.

“No, I don't think they [women] think about it at all ‘cos they don't understand that the radiotherapy goes through the vagina, they just think it goes immediately to the tumour and they don't understand about, unless you explain, they don't understand it will affect the bladder and that. So when I explain I usually say well because the rectum sits so close to the vagina or because it sits so close to the bladder you will get side effects....and then they're like “Oh right”, they understand. But no lay person understands radiotherapy at all so they don't understand that that's how that works.”

[HCP01: Female specialist registrar]
“Researcher: And how much detail did you feel you had about the effects it [radiotherapy] would have on that part of your body, on your vagina?
PT17: Not a lot, I was ehm surprised at the amount of effect it did have in my case. I don't think it was made clear beforehand that it would have a big effect on it....and I'd say my vagina wasn't so much of a problem, but I suppose because I'm not in a sexual relationship.” [PT17: 67 year old woman 15 months post chemo-radiotherapy for bladder cancer]

Although this woman (PT17) had felt she had not been given adequate information about the vaginal changes associated with pelvic radiotherapy she was not concerned by this omission because she was not currently in a sexual relationship. However, the relevance of specific aspects of patient information to individual women can only be determined by the woman herself as illustrated by another single lady who was very angry about not being informed by her surgical team regarding the vaginal changes associated with her radical hysterectomy for endometrial cancer, recounting a discussion with her sister:

“I drew her the picture that [female oncology SPR] had drawn me and said 'This is not like most normal hysterectomies' and said 'they slice off the top third', you know, they slice off the whole top of it and never even told me they were going to slice off the top third. And I said 'how do you think a man would feel if he went in to surgery for a little cancerous lump on his penis and he woke up and suddenly a few weeks later he looked down and realised they had chopped off the bottom third of it.' How would a man feel about that? Just because its inside, it's invisible, you can't see it, doesn't mean to say it's any different, it is exactly the same, but the difficulty for the woman is you don't know what to compare it against. When men go for a pee in the urinal they all stand there, don't they, and I dare say if they play rugby they all shower together, they can see what other men's penises look like. Women, unless I suppose you are a lesbian, but I'm not, but you know women don't know what other women's vaginas look like!”
[PT03: 55 year old woman 8 months post radical hysterectomy / radiotherapy for endometrial cancer]

Within the clinic there were many ways in which the vagina remained hidden or obscured from consideration as a sexualised part of women's bodies. Some women could not recall being told about the specific effects of the radiotherapy treatment on their vagina nor of the sexual implications of such changes but had come to their own conclusions about the likely impact on their bodies and their relationship.

“Researcher: Do you remember them saying much about the effects it [radiotherapy] might have on the vagina itself?
PT06: No, but I'd worked that out myself [laughing]....
Researcher: What had you worked out?
PT06: Well, I had thought that, yeh, you know, this is all going to shrink down, this is, this is the end of it all, you know, eh, as such. And also I think because eh, psychologically, I think your attitude towards sex changes.....ehm, you know, we've always been quite sexually active actually until, until this time....”

[PT06: 72 year old woman 12 months post surgery / radiotherapy for endometrial cancer]

“I thought that the opening to the vagina had shrunk......That's what I thought, because not knowing the anatomy down there. Eh, that's when he [consultant] said we'll have a scan to see exactly what's going on......but I found out subsequently that the vagina went off at an angle! [Researcher: An angle, right!] I thought 'Oh, great!' What next? So we had a good laugh about this. Eh, and then I said we've tried [to have intercourse], a bit of a joke, you know, no way, wow....I mean they've sort of done diagrams and all that but you know unless, I think you've got to be a gynaecologist to understand how these things work. All I can say is penetration is totally and utterly impossible!”

[PT23: 58 year old woman 29 months post chemo-radiotherapy for anal cancer]

This woman had persevered in her attempts to use the smallest vaginal dilator without success and had been persistent in expressing concerns to her treatment team until finally she was referred for a gynaecological opinion and MRI scan of her vagina to determine the extent of stenosis (vaginal length 2-3cm) and intra-vaginal adhesions that made dilation and intercourse impossible.

While some patients and partners appeared to have received adequate information regarding specific changes to expect, others felt they would have liked further detail in order to fully appreciate what impact anatomical changes may have on their sexual relationship.

“PTNR04:.....But if you [wife's name] went in for her operation and clearly they removed a large, they removed a lot of her if you want, and to some extent you don't actually know how much they've removed.

Researcher: No, you don't know how the anatomy has been altered do you?

PTNR04: Right. So you don't know in that sense......and I think, so you don't know what you're getting back.”

[PTNR04: 51-60 year old husband of PT16, a 56 year old woman 24 months post surgery/radiotherapy for endometrial cancer]

As discussed previously in section 7.4.1, distancing strategies adopted by both women and health professionals was evident in the language used to refer to women's vaginas perhaps to separate pathophysiological elements from the emotional and sexual implications of specific vaginal changes being discussed. In referring to their vagina women tended to refer to “if", “the vagina" or “down there" as opposed to expressing ownership of that part of their anatomy. Examples can be seen in data extracts (PT02, PT06, PT11, PT13, PT23)
throughout section 7.4. Objectification was also evident in the language used by health professionals to describe the practices of vaginal douching and vaginal dilator use. These interventions are referred to as “feminine care” by health professionals and, as discussed in chapter six, content analysis of the written patient education leaflets indicates that the emphasis is more on the rationale for this intervention together with technical details of its delivery as opposed to any detailed discussion of the sexual implications of vaginal changes.

At research site A women were given a 16 page booklet that explained the rationale for and technical aspects of vaginal douche and dilator use associated with external beam radiotherapy to the female pelvis and / or vaginal brachytherapy. Information specifically addressing the sexual relationship impact of radiotherapy treatment constituted two pages in the booklet. The language used to refer to the woman’s vagina varied depending on what was being discussed but tended to refer to “your vagina” when technical aspects of the intervention was being described and “the vagina” in discussing the rationale for the intervention:

"Insert the rounded end of the dilator into your vagina gently and press it in as far as is comfortable. The top of your vagina is closed so you won't lose the dilator."
"Both internal and external radiotherapy may damage normal tissue, causing drying of the lining of the vagina and fibrosis (formation of scar tissue)."

[Feminine Care booklet p.9, p.5, Site A]

At site B the equivalent leaflet was called “Options, Risks and Benefits of receiving Radiotherapy to the Female Pelvis” and there was also a short leaflet entitled “Guidelines for patients having High Dose Rate Brachytherapy to the Vaginal Vault”.

In the four page radiotherapy leaflet the content focused largely on the acute side effects associated with pelvic radiotherapy with only one paragraph devoted to “Gynaecological Problems” that explained:

“Following radiotherapy the vaginal wall becomes less supple and therefore narrower than before. This can make intercourse uncomfortable and future internal examinations difficult. You will be given advice on how to lessen this effect with the use of lubricants and dilators.”

[Radiotherapy to the Female Pelvis booklet, p.4, Site B]

In the two-page brachytherapy leaflet the content focused on describing the technical delivery of the internal treatment, with one sentence about side effects of this treatment stating: “You are unlikely to feel any side effects from this treatment.” and referring women with any questions to their radiographer or specialist nurse. There was no mention of acute vaginitis or
the contribution of brachytherapy to any delayed vaginal side effects such as telangetasia or stenosis.

Vaginal examinations performed in the gynae-oncology clinic were also referred to in ways that served to objectify their nature by using terms such as “VE”, “Internals” or “Female Examination”.

The focus on technical instruction of douche and dilator technique was maintained in teaching this intervention to women as identified through interviews with nurses responsible for this aspect of patient education and observation of the radiotherapy treatment review clinics at site A.

“Then my first visit with [Radiotherapy Nurse] here and she went through the douche....and I thought, ‘Oh, the douche’ and she said ‘Yes, because it's to stop, you know...' She didn't actually explain what the douche was for. I mean she explained how, but not why! I worked that out for myself actually later on by a lot of looking things up and looking on the internet and asking those really lovely girls [therapy radiographers] down there.” [PT03: 55 year old woman 8 months post surgery / radiotherapy for endometrial cancer]

The way in which the vagina became objectified and rendered invisible as a sexual place in the clinic was understood as a means to reduce both practitioner and patient embarrassment but may further reduce the likelihood that implications of vaginal changes and the impact of dilation on women's sexual lives would be addressed in this clinical environment.

7.4.3 Changed Anatomy

Vaginal toxicity associated with external beam radiotherapy to the pelvis or vaginal brachytherapy is a recognised late effect of treatment that is addressed with women at key points in their cancer treatment journey as discussed in chapter six. Although rarely mentioned by the practitioners who took part in this study, many of these women also had anatomical and functional changes in the vagina as a result of surgical treatment that either preceded or followed their radiotherapy.

Despite vaginal toxicity only being present as a discussion topic in 29 out of 69 (42%) observed consultations (section 5.2.) vaginal changes were a common discussion point during participant interviews. The range of vaginal toxicities discussed during interviews with health professionals mirrored those presented in table 6.1 and so will not be further discussed here. Health professionals tended to outline the common toxicities they would discuss with women,
often linking such discussions to the rationale for vaginal dilator use or resumption of intercourse in reducing the prevalence or severity of changes such as vaginal stenosis.

"I mean one thing that surprises you when you go through training in radiation oncology or clinical oncology is the number of, for example, vaginal side effects. I had no appreciation of that until I started doing some gynaecology and realised that vaginal stenosis is almost one hundred per cent after brachytherapy unless you can avoid it by intercourse or dilators. And a lot of patients aren't having intercourse for a variety of reasons and I think the compliance [with vaginal dilator use], my impression of compliance with the ladies is that it is very poor, especially in older patients."

[HCP03: Male clinical research fellow]

"And then consider the side effects of those treatments specifically and for me that would be specifically on the ovaries and on menopausal status and then the vagina itself. So thinking about vaginal lubrication and you know, stenosis or shortening of the vagina, so specifically start talking, you know, from the actual of what's happening physiologically."

[HCP09: Female clinical nurse specialist in gynae-oncology]

"And saying that using the dilators, or your husband, partner, would actually help reduce that [stenosis] anyway so it's something that would get better with time and that some people might still have a little bit of bleeding because the walls [of the vagina] can be very thin."

[HCP17: Female Therapy Radiographer]

However, linking the discussion of vaginal toxicity with sexual implications by health professionals was contradicted by both the low prevalence of sexual concerns as a discussion topic in observed consultations (section 5.2.) and by findings from women's interviews. This suggests a dissonance between what health professionals believe to be appropriate patient education regarding sexual well-being after pelvic radiotherapy versus what is subsequently achieved in the reality of every day practice.

The women's narratives about the vaginal changes or side effects they had been informed of or had noticed following their cancer treatment ranged from brief, factual and relatively superficial accounts to lengthy and at times emotionally laden personal stories.

"Researcher: Do you remember anything being said about the effects that might happen weeks or months after radiotherapy, was there something that stuck in your mind at all?
PT02: I think was the tightening of the vagina and sex could have been a problem because of that, and the soreness."

[PT02: 51 year old woman 12 months post chemo-radiotherapy for anal cancer]

"I didn't know about the vaginal collapse thing, that was news, and [outpatient nurse] who explained all that explained it quite logically and that was enough for me."

[PT11: 59 year old woman 12 months post surgery/chemo-radiotherapy for cervical cancer]
“Researcher: Do you remember anyone talking to you about what the radiotherapy might give in terms of side effects to your vagina or to your sexual health?

PT13: Yes they did. They told me that it could shrink and I needed to douche, is it douche? Once a week, yeh. And I think I still have problems in that particular area [vagina] [Researcher: Right, OK] Though I used to do what the nurses told me to do but I still, I still experience pain when I’m having sex.” [PT13: 32 year old woman 16 months post surgery/chemo-radiotherapy for cervical cancer]

One of the women interviewed who was also an obstetrician and gynaecologist and appeared to study the vaginal changes in her own body with a somewhat detached biomedical objectivity, using her vaginal dilators as a form of vaginal manometer:

“They were saying that the radiotherapy would shorten.....in the long term that my vagina will be definitely shorter than before by three centimetres or more. And I did, to be honest, I didn’t have much of a problem with my vagina. The dilator I used, it’s just out of interest because of the shortening of the vagina, and believe it or not it doesn’t bother me. It doesn’t. But I just er, the dilator which I use I measure the length for my own interest.” [PT18: 46 year old woman 6 months post surgery/radiotherapy for endometrial cancer]

In contrast to the biomedical discussions of vaginal toxicity offered by health care practitioners and the brief, factual accounts of some women there was a high level of emotional content in the language used by others to describe vaginal changes emanating from their illness and treatment experience. In recounting the vaginal side effects discussed with them a number of women disclosed the personal meaning they had attributed to these changes.

“No, but the thing that horrified me that I mentally found really offensive, was all the stuff that’s going to happen to my vagina, actually, I had a very strong emotional....the fact that it was gonna get small, shrink, get, you know, shrivel and you know, that seemed very offensive, an outrageous thing to happen, yeh, so I was very affected by that.

......but when the doctor was saying ‘Oh your vagina is going to be 3 inches long’ and a tiny old lady vagina.....it’s a shrivelled small wrecked thing” [PT01: 45 year old woman, 21 months post chemo-radiotherapy for cervical cancer]

This woman had such a strong emotional reaction to the potential changes in her body that she could not touch her vagina and avoided using the vaginal dilators she had been given (section 7.4.5 The intrusion of dilators). She had created a powerful imagery around the internal changes she imagined were present in her body and this woman may therefore be vulnerable to experiencing difficulties in post-treatment sexual adjustment.
I mean I would never stick my finger up my vagina, you know, I can't, I don't wanna touch it. It's....for a long time it was like a nuclear war zone. Just keep out....Chernoble....don't go anywhere near it. Don't wanna think about it, don't wanna touch it.”

[PT01]

Later in the interview this woman disclosed that she was receiving counselling and felt she would recover and overcome the negative feelings she was experiencing about her sexual identity. She acknowledged she found it helpful to use humour to cope with how she felt about the prospect of resuming sex with a new partner given the vaginal changes she anticipated and the difficult associations she now had between cancer and sex:

“Well my joke is always you put a notice in the personal column saying 'Man with small penis wanted!' [Both laughing] No-one will apply!”

“....So it doesn't feel like I'm gonna have too much problem when and if I find a sexual partner it's more the emotional stuff that someone's gonna give me cancer by having sex so....” [PT01: 45 year old woman, 21 months post chemo-radiotherapy for cervical cancer]

Some women and partners felt they had either not been told about or had not fully appreciated the anatomical changes that would result from their treatment or that they or their treatment team had underestimated the severity of the radiation reaction to that part of the women's bodies.

“....what caused me most anxiety was the sort of dawning realisation that something had happened, you know, something physical had happened to my vagina that I didn't know about and it was part of the reason I didn't examine myself, ehm, because I was frightened. I was terrified of what I was going to find, and when I did it freaked me out, mildly freaked me out because it seemed to me that I didn't have anything left. I found the whole thing absolutely, absolutely grim and just, you know, there was no.....I just thought I am not a woman any more, I don't......small....I don't have a vagina any more, I don't have anything anymore and nobody told me this was going to happen. And you can deal with it if you are told in advance because you can factor it into the equation. You can build it into the whole thing but, you know, I mean buggar the bladder.....I feel a non woman!” [PT03: 55 year old woman 8 months post surgery/radiotherapy for endometrial cancer]

“And I just thought what is she on about? Because this is right at the beginning [of treatment] and the douche and all the rest of it and I just thought to myself, you know, she's being a bit over the top here, isn't she? Not realising how bad it was going to become. So I think that was the most shocking, significant thing for me and I am not sure that I was told how bad it was going to get. But then you know it's very subjective I suppose, isn't it? So I don't remember being told it was going to get so swollen and tender and sore and that I'd lose my pubic hair and I suppose, you know, not only
physically was it very very sore and painful but psychologically I just thought, I was shocked by the appearance. Mmm. And during that time of course, you know, I wouldn’t let my husband anywhere near me [Both laughing] No way just, you know, go away and never come back sort of thing![Laughter].” [PT09: 50 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

“I think they underestimated the degree of tissue damage that had happened and, in doing so, I won’t say they raised false hopes, that’s not really the point, but I think that was there was a discussion about it [sexual recovery] and they said ‘No it will be OK’ but clearly it wasn’t going to be OK.” [PTNR04: 51-60 year old husband of PT16]

Although most of the women had experienced some degree and type of vaginal toxicity some had resumed sexual relations with their partner without incident:

“Physically there wasn’t that much difference. Perhaps I was a little bit dryer and things but I didn’t feel any real differences, you know, differences that didn’t change [sex] anyway.” [PT05: 36 yr old woman, 12 months post surgery / chemo-radiotherapy for cervical cancer]

Others continued to experience sexual difficulties (PT13) as discussed in more depth in the next chapter. Some women had encountered initial sexual difficulties but had overcome them through effective explanation of the specific vaginal changes, allaying partner anxiety:

“And we first had it he was slightly uncomfortable because you could feel, because its obviously got shorter, the vagina. And, ehm, you can feel it hitting up against a brick wall that’s there now. But it was assuring him that it was OK, you know he wasn’t, you know, really doing damage at all, he was concerned then that if he penetrated too far then he’d rip all the stitches open or something.” [PT14: 63 year old woman 4 months post surgery/radiotherapy for endometrial cancer]

While the majority of women commented solely on the vaginal changes they had noticed in relation to penetrative intercourse, this particular woman was interesting in that she had also noticed how her orgasmic response had been altered as a result of her cancer treatment. She described accurately the altered sensation she now experienced as a result of having had her uterus removed.

“And when we start stimulating around the clitoral area and you can feel, and I always feel the womb moves up when you’re getting, you know, sort of near it [orgasm] and you can feel these sensations….and it’s not there [now] and I don’t know, well I haven’t got a womb to move any more. But, ehm, sort of it’s [orgasm] not the same.” [PT14: 63 yr old woman, 4 months post surgery / radiotherapy for endometrial cancer]
Another woman who had developed a particularly severe vaginal stenosis and tissue reaction following chemo-radiotherapy for an anal cancer described changes in her clitoris and how her vulval and perineal area felt like “hard butter” leading her to feel ugly and unfeminine.

“I was so glad when they kept off the front [changed treatment field] I mean I really was in a bad state, you know, the clitoris had gone rock hard.
Oh it’s horrible, just, I can only call it hard butter……it’s smooth and hard……There’s nothing else you can say about it. And it is distressing because, you know, you like to think of yourself as being, I feel very unfeminine……Because it’s ugly, the pubes are, struggling, you know, couldn’t believe it!”
[PT23: 58 year old woman 29 months post chemo-radiotherapy for anal cancer]

Other women spoke of a combination of vaginal and bowel side effects and functional changes that collectively impacted on their sexual lives:

“PT19: ….he would have difficulty getting in to start with [achieving vaginal penetration]. Ehm, it’s not so painful when he does ejaculate, it’s a, it’s a lot better than it was in the very beginning [experiences burning sensation in vagina from partner’s semen]. So whether I’m healing there……My problem, diverting from your train of thought, ehm, I’ve been affected in all of that area with my muscles from the treatment. I have no muscle control at all, so I don’t know how I can control those muscles in the vagina because I can’t control them in my bowel and I have difficulty controlling them, you know.
Researcher: Does that mean sometimes you have a bit of leakage?
PT19: Yes, I wear a pad all the time.
Researcher: Right. And is that quite difficult when you think about that in conjunction with being intimate with somebody or is it something the two of you can manage okay?
PT19: I manage it. I don’t know. I have this theory that the body reacts accordingly and somehow it’s not an issue, I’m controlling it I suppose partly with my diet. That makes a fair amount of difference, for a while it wasn’t that easy, I was leaking an awful lot in both parts of me.”
[PT19: 62 year old woman 17 months post surgery/radiotherapy for endometrial cancer]

In addition to the magnitude of anatomical and functional changes experienced what appeared particularly important was the personal meaning the women ascribed to the changes they had noticed and whether or not this could be re-framed more positively for the woman or couple. One of the women joked about the positive way in which she and her husband viewed the vaginal narrowing she experienced following her chemo-radiotherapy and abdomino-perineal resection for rectal cancer. As a mother of four children she remarked that her previously “floppy” vagina had become virginal once more:

“….I mean since my surgery, obviously, ehm, I feel as if my anatomy had changed completely and the surgery is so brutal, ehm. But again, you know, I did recover extremely quickly physically…. 

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Researcher: When you think of your experience of making love to your husband after your treatment did you feel a different person after your treatment?

PT09: Eh, well I felt physically different, I felt like a virgin. Eh, very, very tight......very, very tight which, you know, heightens the experience really for both of us, so I mean [husband's name] thought it was marvellous!"

[PT09: 50 year old woman 12 months post chemo-radiotherapy/surgery for rectal cancer]

Another couple who had noticed anatomical changes caused by cancer treatment during sex were PT10 and PTNR 02. This 68 year old woman had been treated by chemo-radiotherapy and an anterior resection of her rectal tumour 24 months previously and had always enjoyed a regular sexual relationship with her husband. Following resumption of sexual intercourse she described her awareness that “The vagina shrank” and that her husband had told her she felt different inside compared to before her treatment.

“Yes, I think it narrowed. I don't know if it got shorter because I actually have quite a long one [vagina] apparently, but, and that was awful and in fact we didn't make love most of the time, any of the time when I had that [colostomy], I just couldn't. And I didn't want to do anything else either. Eh, I think that's [vagina] all recovered but [husband's name] will tell you differently. He says I feel different......He says, he says things feel thicker he described it. But I'm not aware of that.” [PT10: 68 yr old woman, 24 months post radiotherapy / anterior resection for rectal cancer]

“PTNR02: But certainly the fact that she's a different shape has made it more, I'd say more difficult, eh, in the early stages obviously she found it uncomfortable. Eh, but I mean that was simply because she, eh, but with the, or the gadgets and things she got, you know, eh, with the stretching and all the rest of it and then. [Researcher: The dilators?] Yeh, that's right. I mean they obviously helped and then actually having intercourse [helped].

It was less easy to get in......I mean her shape inside is different.

Researcher: Right. In what way does it feel different, this is quite interesting.

PTNR02: I was going to say the lumps are in different places. It does feel different, I wouldn't say there's less space but also, even now, well I say we're not as probably as relaxed as we were before…” [PTNR02: 61-70 year old husband of PT10]

Although this couple had not placed such a positive interpretation on the sexual implications of these vaginal changes as PT09 and her husband (PTNR01) they had been able to accommodate the changes and with the assistance of extra lubricant were able to continue to engage in comfortable intercourse on a regular basis.

The diversity of physical changes combined with both psychological and relationship responses contained in the interview extracts presented in this section illustrates the complexity and challenge inherent to clinical assessment of sexual morbidity arising from cancer treatment. Fundamental to identifying women or couples who may be at higher risk of
developing sexual difficulties post-treatment is a greater understanding of the personal meaning that people ascribe to the anatomical and functional changes brought about by multi-modality treatment.

7.4.4 The Meaning of Blood

As discussed in chapter five, vaginal bleeding was a prominent symptom in follow-up consultations where vaginal toxicity had been discussed, occurring in 17 out of the 29 (58.6%) observed consultations.

Compared to other vaginal changes bleeding from the vagina appeared to hold a particular personal meaning for some of the women, especially where this had been the symptom that had led to their cancer diagnosis. As this woman graphically described her experience of vaginal bleeding associated with intercourse before her diagnosis:

"PT04: The number one, the minute I saw the blood that was it.
Researcher: When you say 'that was it' does that mean you didn't want to be sexual with your partner?
PT04: Yeh, because when I did have blood it, it really poured, leaked out at one time and I did actually feel, this was before I had it done at the [name of treatment centre]. At one time you know different men have got different size, well he is quite a big man size and I felt something and then as I felt it hurt and as I, it pushed in further it stopped and oh, the blood that came was terrible.
Researcher: That would be quite frightening, I imagine.
PT04: Yeh, it was frightening because I didn't at that time know what it was. And then your mind goes bobbling, don't it, cancer...."

[PT04: 64 year old woman, 8 months post chemo-radiotherapy for a stage IIIb cervical cancer]

For this woman the fear of seeing blood from her vagina was sufficient that she avoided sexual intercourse altogether or was worried and preoccupied during intercourse that she might bleed again.

"PT04: Yeh, you see it's, it's funny how your mind can take over yourself, so then when it was all finished I did try it [intercourse] a couple of times but I was really dubious, you know. And, and as the months got passed it wasn't good sex because in my mind as I say to you, I think I was half to blame with this, well a lot of it actually to be honest with you, because it's in my mind that I was frightened I was going to see blood.
Researcher: Right, so that was in your mind when you were....
PT04: And do you know what, when I lost all this, this blood, eh, because I'd lost a bit before I put a big towel on the bed and in my mind I can still see that towel with all that blood on it....so then it [sex] got quite, well not that good at all.....because I was frightened to let him put it fully in......I'm frightened of seeing blood again and I'm still like it."

[PT04]
Women were uncertain regarding what amount of bleeding could be considered "normal" within the context of treatment induced vaginal changes versus what was a sufficient amount of blood to approach their treatment team for further advice.

"Because they, they don't expect that. Could be just a tiny bleeding, for them bleeding is a cup full of water, so I say oh just a small amount of blood they think Oh, that's nothing but actually when they see it [blood] they get frightened so they, they will phone." [HCP15: Female outpatient staff nurse]

"PT23: And I found that ehm there was a little bit of blood, ehm...
Researcher: When you'd used the dilators?
PT23: Not bleeding but there would be blood on the, on the top, right on the top [of the dilator]
Researcher: Mmm, little flecks, yes, spotting, yes.
PT23: So, ehm, you know, not knowing what the hell was going on up there [inside vagina]." [PT23: 58 year old woman, 29 months post chemo-radiotherapy for anal cancer]

In some instances fear of inducing vaginal bleeding through dilator use was either viewed as an unpleasant reminder of their illness or led women to stop using their dilators rather than contacting their treatment centre for further advice.

"It's a reminder. Ehm and I don't know, I don't think there's any way of how you cope with that, I think it's just something that's in me, that's how I feel about it. That I, you know, you do this dilator and I'm always thinking Gosh, you know, I'll have to see if there's any blood, is it, you know, and it's that. And it's silly really but it's, it's quite a big thing in my mind to get over that. I mean in every other respect I have, you know, I just get on with life and don't think about it, but this is a constant reminder." [PT21: 54 year old woman 18 months post chemo-radiotherapy for cervical cancer]

"...I didn't start it [using the dilator] for about six months after the operation. I was probably a bit more worried about what was going to happen, and then I was doing it fine. But it was just that one morning I done it and there was all blood down there and I thought, Oh my God! Ehm, because it worried me and I thought why, have I got something wrong with the vagina now? And then when I had the, I think it was November, I think I came over for a check up and they said No, everything's fine. That was good because that relieved me and I thought that's good, that's OK. But I must admit I haven't really tried the, ehm, dilator for ages." [PT07: 63 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

As a result of the anxiety associated with dilator use, and in the absence of enquiries regarding compliance or support with this intervention from her treatment team, this lady did not use her dilator. The lack of regular dilator use and vaginal changes caused by both her
radiotherapy and surgical excision of the posterior vaginal wall led to severe vaginal stenosis and meant that this couple had not been able to engage in sexual intercourse at all post-treatment. At times women had not disclosed that they had experienced bleeding during sexual intercourse with their partner but when bleeding was elicited as a result of vaginal examination in the clinic then the significance of this symptom for both the woman and the health professional could be explored.

"Last Friday I was in clinic with a young girl who was only like twenty eight or something and when I examined her she had quite a lot of bleeding and then, then that sort of opened the door to asking her, and she was there with her partner, and opened the door to be asking about what, what was her sexual function like? And then it opened up that can of worms. She hadn't mentioned any of this at all, I said are you well? Everything fine? Blah, blah, blah, everything was fine. I examined her, she had quite a lot of bleeding and then when I asked her, when I actually asked one of the consultants to see her because I was a bit concerned there was quite a lot of bleeding and then you say to her.... Oh well, she said, actually I've been getting quite a lot of bleeding after intercourse but I didn't want to ask anybody about it."

[HCP05: Male specialist registrar]

The potential significance of vaginal bleeding associated with sexual intercourse or vaginal dilation was endorsed by health professionals who were responsible for evaluating the nature of the bleeding in order to differentiate between the "spotting" associated with thinning of the vaginal mucosa, telangectasia or the breaking down of vaginal adhesions by dilator use from that which might indicate vaginal recurrence of the woman's cancer.

7.4.5 The Intrusion of dilators

As discussed in section 2.5.2, although the efficacy of dilator use in preventing the development of vaginal stenosis remains unproven, the majority of radiotherapy departments in the UK advocate their use as the dominant intervention offered to women who have received pelvic radiotherapy where the development of vaginal fibrosis, stenosis or shortening is considered likely. However, despite their widespread use there remain inconsistencies in relation to the target population of women who should be given dilators (White & Faithfull, 2006). This inconsistency was evident between research sites A and B whereby research site B did not appear to have systems in place for the delivery of feminine care advice and dilator provision to women treated for non-gynaecological malignancies. As their colorectal clinical nurse specialist (CNS) explained:
"I haven’t known any patient to be given anything like that....I might be wrong but I am not, not knowingly.....Having said that many years ago, she’s retired now, the gynae nurse specialist I used to share a big office with her and it was very well known that she gave patients dilators. Whether that’s still in practice now I don’t know but she did, but as far as our rectal cancers are concerned nothing was given.”

[HCP12: Colorectal Clinical Nurse Specialist, Research site B]

In addition to illustrating the inconsistencies in delivery of this intervention to women receiving radical pelvic radiotherapy, regardless of their primary diagnosis, this comment also corroborates the relatively low profile given to vaginal toxicity and dilator use in the supportive care of women with non-gynaecological malignancies. This practitioner did not know about current practice within the radiotherapy department regarding dilator provision and had not enquired about dilators for her own patient group (women with rectal or anal cancer) as she practised predominantly within the surgical directorate of the hospital.

Vaginal dilators are usually plastic cylindrical shaped cones provided in graded sizes and women are asked to insert them into their vagina at a frequency of two to three times weekly while they are not having intercourse in order to stretch the vaginal walls and to break down adhesions that may form at the top of the vaginal vault.

Clinicians and women appeared to view the use of vaginal dilators as an important prophylactic intervention to ensure vaginal patency both from the perspective of disease surveillance and the resumption of sexual intercourse post-treatment. However, despite the apparent legitimacy of vaginal dilator use within clinical oncology, compliance with this intervention was not routinely monitored by health care professionals.

Established systems of care also failed to ensure that all women who should receive vaginal dilators did so, illustrated by the fact that out of 24 women interviewed, four of them had not been given dilators (PT 13, 15, 22, 24). Omissions in feminine care advice and provision of dilators was also evident during the participant observation period of the study where I identified seven women who had not received a set of dilators despite having completed radiotherapy over three months previously together with a number of consultations where in the absence of any discussion from the medical practitioner I would raise the issue as a point of clinical care provision. Although intervening during the consultation created an ethical dilemma for me in my role as participant observer, as a cancer nurse I felt I had a duty of care to ensure the woman was referred to the radiotherapy department to receive this aspect of her care delivery without further delay.
During interviews with clinicians a number of them alluded to the provision of vaginal dilators and the rationale for their use. At the same time there was an acknowledgement that many women did not persist with the use of dilators perhaps because they are not aware of their importance in the prevention of vaginal stenosis.

“Well I suppose they get seen by the radiotherapy nurse and told to use dilators but then probably lots of them don’t bother and don’t understand why [they should use them]. And then it’s lost unless the doctor specifically asks.”

[HCP01: Female specialist registrar]

“....a lot of patients aren’t having intercourse for a variety of reasons and I think the compliance, my impression of compliance with the ladies is that it is very poor, especially in older patients.”

[HCP03: Male clinical research fellow]

Analysis of participant observation data (see section 5.2) revealed that discussion of the provision and use of vaginal dilators was only present in 16 (23.2%) out of 69 observed consultations and usually followed discussion of vaginal toxicity. One of the specialist registrars also illustrated this link in discussing how he used signs of toxicity elicited during vaginal examination to introduce the topic of dilator use and to create the opportunity to enquire whether or not the woman had resumed sexual intercourse with her partner:

“I often find myself in a situation after I’ve examined them, you know, and then like it’s very uncomfortable and you say you’ve got adhesions, did you use a dilator? Did you do this, are you sexually active? So, and I use it to prime patients as to why we recommend douches, why we recommend dilators.”

[HCP05: Male specialist registrar]

The provision of vaginal dilators usually fell within the remit of either radiotherapy nurses or therapy radiographers within the radiotherapy departments. However, these clinicians were not present in the follow up clinics where there was more opportunity to enquire about ease of use and compliance with this intervention post-treatment.

“Researcher: If they are not using their dilators would they ring and tell us or not, I don’t know what do you think?
HCP11: Eh, yeh. Because they come back to clinic 2 months after. I don’t know what the doctors ask. I think they should do with something that if they’re not using it they should send them down to me.”

[HCP11: Female radiotherapy department nurse]

As there was no formal mechanism by which compliance was evaluated the responsibility for asking women about dilator use appeared, by default, to lie with medical staff. Yet as this
registrar acknowledged, medical staff tend not to be given specific training in the management of vaginal stenosis through the provision of vaginal dilators.

"I mean once I've offered vaginal dilators and given them the, you know, the advice and the pack. I just assume they use it, I never really follow up whether, you know, it's practical for them because for some it might be quite, you know, been difficult to insert ehm and so I never really follow that up. And I assume that [Gynaecology CNS] picks that up but ehm, she probably doesn't with every patient. And there are no guidelines really on you know, when to start them, how long you take them, so if you haven't done a job where you know there is an emphasis on it, you don't know and you're not trained in these aspects."  

[HCP13: Female specialist registrar]

There was no continuity of personnel between those providing the dilators and patient education and those responsible for monitoring post-treatment vaginal health and sexual recovery. This low frequency of discussion about the use of vaginal dilators within follow up clinics may also serve to marginalise any focus on vaginal and sexual recovery over the biomedical focus on vaginal toxicity.

In the provision of vaginal dilators practitioners spoke of the dilemmas they faced in establishing whether or not a woman was likely to comply with the request to use dilators or where patients had refused to use them despite awareness of their perceived benefit to disease surveillance and, where relevant, to sexual recovery.

"If somebody has got mental illness, if they are not necessarily going to understand, if they are very elderly and frail and are not going to manage to use dilators, if they don't want to......we did have a lady in her fifties or sixties, she was ehm single and a virgin and didn't even know where her vagina was. So, in actual fact, you know, she was frightened of using douches and dilators and she actually had to come and insert it and show her where it was and everything, go through a lot with her. Ehm, when they do come to us we go through with them about the reasons that are behind actually needing ehm, douches and dilators, what feminine care really is."

[HCP07: Female radiotherapy department nurse]

The staff directly responsible for this aspect of patient education largely demonstrated awareness of the sensitivities surrounding dilator use and had adopted personal strategies for managing these issues with women who were often feeling overwhelmed by the demands of their illness and treatment. One nurse spoke of the distinction made between the need to use a dilator to maintain vaginal patency versus the desire to engage in sexual intercourse, both of which contributed to promoting vaginal patency.

"Really that [dilator use] shouldn't interfere with the sexual aspect of, you know, that sex should also, should still be that intimate act really. I think for some people, there are some women who will say oh well, there was one woman who did say, 'Oh well I'll
just have sex instead.' And I know I said to her well, you know, there isn't necessarily everyone who will have it [sex] three or four times a week."

[HCP07]

While another nurse encouraged women to engage in regular sexual intercourse as an alternative to dilator use, acknowledging the distaste some women experienced associated with their use.

“I don’t feel that, that you know the dilator should be as a sex subject because, because it isn’t, it’s not a substitute for a man, so I’m pointing out the benefits from it [dilator use]......Because they see a medical reason for it and I believe they will do it. Because it’s not a very nice thing to do, I mean come on, if you are a grown up woman and you have a sex life and you’re given something hard and horrible [dilator], they don’t find that attractive. But if you tell them it’s important to keep the vagina open and dilated because otherwise nobody can see inside, and you give them the reasons, they are quite happy to do that.
......And if you explain to them that it [dilator] is hard and it’s not very nice that you know, because the way that I am saying to them if they’ve got a husband, I try to encourage [ them] to resume their sex life because that is the easiest way and after I showed them the dilator and I said look it’s just hard and it’s not pliable, you can with your husband you know, you’ve got feelings, you’ve got, you know, commitment and everything there so it’s much easier.” [HCP15: Female outpatient department nurse]

These practitioners also demonstrated awareness of the emotional burden and sense of intrusion that some women experienced in trying to comply with clinical advice. As one staff nurse explained:

“At the end of the treatment if they are still sore they really don’t want to think about using dilators......And to be thinking of them for long term as well. When they are quite young it’s the thought of, ‘Oh no’ and it reminds them that they’ve had cancer and they’ve actually had treatment. For some people it would be almost a regret that they had the treatment.
And I suppose in a way we have to allow patients to make that decision [whether or not to use dilators] because it is asking a lot of women, I think, to do something relatively intrusive to their bodies” [HCP07: Female radiotherapy department nurse]

One therapy radiographer felt that using dilators could have adverse effects on the woman’s interest in sex because of the emotional reaction they may have to being asked to use dilators after treatment had finished:

“There’s nothing worse for people’s libido than to have these things [dilators] and the husband is too, I think, they’re probably frightened too.....Some women obviously are a lot more clued up and they’ve read the leaflets, they know about dilation and it’s not come as a surprise. Some haven’t read anything so it comes a as terrible shock to them the thought of after the treatment’s finished they’ve got to do anything, especially

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if they haven't had penetrative sex for some time. Some people find it [dilation] quite
distasteful.
I mean I have said to one lady, really she said I really can't cope with doing it. And I
said well that's your choice, nobody's going to make you do this. You explain the
reasons why but they really find it distasteful to do anything to that part of their
anatomy.”

[HCP16: Female therapy radiographer]

Her colleague commented on the recently published national guidelines for dilator use in the
UK which she felt addressed the practical management of the intervention at the expense of
acknowledging how difficult it could be for clinicians to support women in the emotional
reactions they had to being asked to use a vaginal dilator or undergo vaginal insertions for
vaginal brachytherapy.

“I know there are national guidelines [about dilator use] but they don't really, I don't
think they are adequate. They don't address how personal it is! It does talk, it's a
physical thing, but it doesn't talk about if you're a seventy year old woman and you've
got arthritis in your hips, how are you going to manage? If you are on your own, a lot of
the practicalities of it and how are you going to feel about it? Well we do still get
seventy year old unmarried women who've never had a sexual partner who look at
these things [dilators] in absolute horror. Some women actually have a laugh about it
but some of them are very embarrassed especially if they go to the HDR suite and
have the internal treatment [vaginal brachytherapy]. I don't know if you are aware of
the size of the applicators?”

[HCP17: Female therapy radiographer]

A small number of the women interviewed were neutral or adopted a pragmatic approach to
having to use dilators on a weekly basis.

“Researcher: Do you remember what was being said about the need to use them
[dilators]?
PT20: Just to, yeh, just so it keeps it [the vagina] open, mmmm.
Researcher: Right. How did you feel about having to use something like that?
PT20: It didn't bother me....I'm quite open minded, you know, I'm not a prude or. I'll try
anything really, I'm that sort of person, it didn't bother me.
Researcher: Are you still using them now at this stage?
PT20: No. Because it was a couple of months and then we started having sex again so
no, I haven't used them since.” [PT20: 33 year old woman 21 months post chemo-
radiotherapy for cervical cancer]

“So it would have been a good idea to have had them straight away after, you know,
that you are OK after the operation and everything's healed up OK. Because you know
once I started using those [dilators] I was getting little bleeds but nothing, you know it
was just in the jelly on the thing [dilator] and eh I put a pad on but there was nothing,
nothing flowing. And obviously I don't bleed after sex so it was just opening up the
passage I suppose.” [PT14: 63 year old woman 4 months post surgery/radiotherapy for endometrial cancer]
However, the majority of the women had varying degrees of negativity towards their use. As one might expect, those women who were most distressed at the nature of vaginal changes induced by their treatment also found the greatest difficulty in using dilators to manage the vaginal toxicity they had encountered.

“To be honest I hardly ever, I hardly ever do it [use dilators]. I don’t find them repugnant anymore, I found it at first. I found the idea humiliating, the idea that this should happen to me was, I had always regarded myself as quite attractive and that I had a funny old lady weird vagina that these kind of weird things.....you know, utterly humiliating and obscene, I found it.” [PT01: 45 year old woman, 21 months post chemo-radiotherapy for cervical cancer]

For others the need to use dilators was a reminder of their illness when they were trying to resume normal life again and thus dilation was experienced as an intrusion:

“It is an intrusion and I, not that it hurts or anything like that when he, you know, you go through it but it is very, it becomes almost a different part of your body, part of me, and because subconsciously I think I would be, I do find I have to say not actually the actual doing of the dilators, but the actual thinking that every time I do this I am always aware of looking for signs, you know, is there going to be lots of blood? ....And it’s all of those sorts of things and so one is always aware and trying so desperately to forget it and yet t comes back all the time because you’re doing this [dilating] so regularly and therefore although you build, you build it into a routine, but it brings it back every time.” [PT21: 54 year old woman 18 months post chemo-radiotherapy for cervical cancer]

In contrast to the emotions dilator use generated for the majority of women in the study, some of them felt that certain staff were too objective towards the “routine” nature of dilator use and that they failed to recognise women’s emotional reactions to using a device in such a private part of their bodies.

“She sort of talked about the vaginal dilator and she sort of gaily said things like ‘Well you’ll have to use that for the rest of your life’ which is a pretty daunting prospect and, you know, pretty horrible and pretty scary frightening.” [PT03: 55 year old woman 8 months post surgery/radiotherapy for endometrial cancer]

The view of this patient was endorsed by another woman (PT11) who had also objected to the same staff member’s somewhat flippant attitude and by comments made by the practitioner herself when talking about the way she addressed feminine care advice.

“No, I bring it [dilators] and I say have you got your feminine care booklet that I left for you and I open it [demonstrating opening dilator pouch], it’s always laughter, it’s
always light, always sort of 'oh, I'm going to have fun' and all that and go about it then..."

[HCP11: Radiotherapy Department Nurse]

My personal interpretation of this practitioner’s approach, as witnessed during participant observation, was that she found addressing this aspect of care embarrassing and daunting and so she used distancing tactics and humour to try to manage both the women's and her own embarrassment and emotional reactions to this aspect of supportive care.

Generally women were given advice about vaginal dilator use on a one to one basis or occasionally with a friend or partner present. However, one of the women recalled three patients being given advice in a small group in the radiotherapy department and expressed concern in relation to the impact this group approach may have had on two women whose personal circumstance were not as favourable as her own.

“When I went for the internal radiotherapy, when we had the little group discussion with three ladies and myself..... with a lovely Malaysian nurse who came with little packs of dilators and everything and talked about being sexually active and I think that was the first time really that anybody had sort of talked about it. And the lady who didn't talk much said 'sexually active would be a fine thing if only I had a man.' And the lady that's prognosis wasn't terribly good said 'That's the last thing on my mind.' And I think I just sat there and nodded because these were two very sad people and I got the support of [husband's name] and everything and I didn't want to shout 'Oh I've got a lovely husband' when people have horrid things going on. So she gave us the dilators, told us that if we were currently sexually active, bearing in mind this is still only about six weeks post op, that we didn't need to worry about it, but if we weren't then to use the jelly and the thing [dilator].” [PT11:59 year old woman 12 months post surgery/chemo-radiotherapy for cervical cancer]

This extract demonstrates the potential hazards of approaching something as sensitive as vaginal health and potential resumption of sexual relations for women who may have very different personal circumstances and thus need an individualised approach that is sensitive to their needs.

Very few of the women could recollect being asked specifically about whether or not they were using their dilators, about frequency of use or whether or not they had experienced any difficulty in their use. On the issue of compliance one of the women who was particularly aversive to using her dilator joked with me about how she would use the dilator prior to seeing her consultant for follow-up so that he wouldn't know she had not been complying with the dilator advice she had been given.

“It's just something that I think 'Oh fuck, I'm going to see [consultant name] next month I better stick it up a few times and make sure it's not closed up. But I mean I think
you're supposed to do it three times a week......I probably do it.....I think after a check up I remember a bit more, but I would say it was......I can go a month without doing it but then I might do it once a week for a couple of times, I mean it's very random.”

[PT01: 45 year old woman, 21 months post chemo-radiotherapy for cervical cancer]

As mentioned previously, there did not appear to be any formal mechanism for checking that women were either using the dilator effectively or able to overcome any difficulties they had encountered. Within the interview transcripts there were numerous examples where women experienced either temporary or enduring difficulties associated with dilator use.

“PT10: Yes I started off with the smallest one, ehm, I went from the middle to the largest I think because the smallest one went in all right. Researcher: And did you find that they were quite comfortable to use?
PT10: Not to start with, no, but with the lubricant I remember they were alright. Yes, I did it after the bath every morning” [PT10: 68 year old woman 24 months post chemo-radiotherapy / surgery for rectal cancer]

“And then go on to the next stage. [progress to a larger dilator] Well I never got past that first stage and 'cause [Radiotherapy Nurse] said the best way to get that sorted out is really to have sort of sex, sort of thing, you know, but we never even got round to that sort of thing because my husband, I think he's a bit worried about going near.”

[PT07: 63 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

The issue of timing of dilator advice and access to specialist support was particularly problematic for women with rectal cancer as they often had their surgery and radiotherapy in different hospitals. Hence the women had been given dilator advice during the first week of their chemo-radiotherapy and were expected to commence dilation approximately four to six weeks after completion of radiotherapy, often coinciding with their admission to have surgical resection of their tumour as explained by PT07:

“When I was in hospital I asked a nurse about doing the dilator and she wasn't quite sure and then I had to phone. I phoned up the [cancer centre] to ask them and [Radiotherapy nurse] said 'Oh do it as soon as you can because you need to keep it [vagina] open' and all the rest of it. So, ehm, and then we started it [dilator use] but I didn't, I must admit, I didn't start it for about six months after the operation.”

[PT07: 63 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

This lady's husband (PTNR03) also remarked on how the couple were largely left unsupported while his wife struggled to use the two larger size dilators she had been given
but which she had found impossible to fully insert because of the reduced vaginal size after partial vaginal resection.

“We’ve been left a little bit to our own devices, as it were, you know, without any direction given to us, you know. Eh, the nurse here she’s very good, she did say something to [wife’s name] about, this is a long time ago now, this is when she had the radio treatment. She said you will have a tightening of the vagina, she said, this is before she had the operation so we didn’t know they were going to slice a bit away, but if you use the dilator she said, and then go to the larger size dilator and then, she said, you should be alright for intercourse after that, you know. But really that was about the only sexual instruction, if you like, that we’ve ever had and then it wasn’t me, just [wife’s name] on her own.” [PTNR03: >60 year old husband of PT07]

7.5 Category Summary

Sexuality was not considered a priority in women’s lives while they coped with acute side effects and fought to become a survivor of their illness. Their emotional and physical energies were devoted to side effect management and beginning re-adjustment to work, family and relationships. This initial period of recovery was also marked by gratitude to their treatment team whereby negative inferences regarding the neglect of their sexual well-being was considered inappropriate in the context of having secured greater likelihood of survival.

Women and partners spoke of altered life priorities in the face of a cancer diagnosis and thus it appeared difficult for health professionals to ascertain the relative importance of women’s sexual lives without knowledge of the meaning women attributed to their illness in the context of individual lives and relationships. The women’s relationship was the defining context for the expression of intimacy and sexuality. Where their relationship was secure and supportive women experienced emotional support and adaptability to any potential changes in sexual well-being. Conversely, where the relationship was conflicted or distant women tended to withdraw in order to manage their emotional support needs and for some the strain of facing a serious illness led to relationship breakdown. Despite the women’s relationship serving a central role in their support post-treatment this aspect of women’s lives was not actively explored or engaged by those responsible for the woman’s clinical management.

Female sexuality was predominantly constructed in relation to its expression within a heterosexual relationship, thus marginalising women who were not currently in a relationship. Where women had experienced a loss of interest in sex as a result of their illness and treatment it was common for them to feel obligated to engage in sexual intercourse to enable
their partner to express his sexuality and for the sake of their relationship. Older women were consistently viewed as asexual by health professionals and by some of the women themselves. Health professionals all acknowledged the greater difficulty they experienced in discussing sexual concerns with women in their seventies and this finding was supported by participant observation data.

Within the follow up clinic female sexuality was also defined by the ways in which women's bodies, particularly women's vaginas, were constructed as [de]sexualised and associated with disease recurrence and treatment toxicity in the context of pelvic cancer and its treatment. Women's vaginas were objectified and became the focus of intense scrutiny or surveillance through routine vaginal examination within the gynaecology clinics while in the colorectal clinics this part of women's anatomy remained invisible unless a source of active symptoms. Women talked about the vaginal changes they experienced as a result of their treatment and of the emotional and sexual meaning they ascribed to this altered anatomy while health professionals tended to distance themselves from the vagina as a vehicle for sexual expression. For many participants the vagina appeared to represent a site of disease, bleeding, discharge and potential contamination. The final objectification of the vagina came from its instrumentation by vaginal dilators to reduce the likelihood of vaginal stenosis and shortening. Women spoke of their distaste at the intrusion dilators made into their lives after treatment. Some developed elaborate avoidance strategies while others complied with health care advice while experiencing dilation as a constant reminder of their illness.

Hence female sexuality after cancer treatment is constructed as one of receptive vaginal functionality within the context of a heterosexual relationship and is largely devoid of sensuality or non-coital sexual expression. Women's sexuality was re-constructed and re-prioritised in their lives as a result of the experience of cancer and continued to evolve within the context of current and future intimate relationships after treatment completion.
Chapter 8: Living with a changed sexual life after cancer

As discussed in chapter seven, women and their partners were aware of a number of physical changes and emotional responses emanating from cancer and its treatment that had affected the nature of their sexual relationship.

In the course of these interviews it became clear was that there was considerable variety in relation to what individuals and couples considered their sexual norm prior to any disruption created by illness or treatment. Some women spoke of an unsatisfactory sexual life prior to their illness while others felt that they had an enjoyable sexual life with their partner, albeit shaped by personal circumstances such as partner availability and lifestyle demands.

“Yes, it wasn't a good sex life before I got ill...... he never wanted to shag me, basically [laughs]....mind you he was a depressive and he was on anti-depressants and, you know, there were other sexual issues, to be honest, which probably aren't relevant here....so there were a number of things, but it [sex] wasn't that often and I didn't feel desired.”
[PT01: 45 year old woman 21 months post chemo-radiotherapy for cervical cancer]

“Sexually I'm, you know, not very sexually active anyway because of the fact we have kids and we have the constant routine of, you know, trying to fit everything in to such a small amount of time. And you know there are periods of time when we don't have, you know, a tremendous amount of sex, but I think that's normal for a large family or anyone that's working. I mean he's working, I'm working, you know, it's that kind of thing but I wouldn't say we have any particular problems.”
[PT05: 36 year old woman 12 months post surgery / chemo-radiotherapy for cervical cancer]

“Oh well I would say we had, you know, a healthy, normal sex life. Ehm, he does work away. He works away from [home], well he goes very early on a Monday morning and comes back on a Friday evening, so we spend the weekends together, basically. But I mean we had sex well at least once or twice a week, at the weekends. Ehm, and it's never been an issue, that's the way we do things.”
[PT09: 50 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

The normality of a relatively low frequency of sexual intercourse was a frequent comment among this group of women, but for most when sex did take place it was experienced as an enjoyable and relationship affirming activity.
"To be honest, you know, I didn't have that kind of a desire, you know, number one. But it's really, I don't, to be honest, in all my life, you know, it's been my work. Sex, it was really the last thing I would ever think about."

[PT18: 46 year old woman 6 months post surgery/radiotherapy for endometrial cancer]

"Researcher: How would you describe your relationship with your partner prior to your illness?
PT21: Absolutely what I would call normal. You know, we had a normal relationship. Very caring, and it still is, you know, but it's never been I suppose, sexually it's never been a big thing for me, for both of us, it's not been the be-all and end-all of anything. And although, you know, it was something we did and we enjoyed, it wasn't something that I, it wasn't going to be the main thing in a relationship at all."

[PT21: 54 year old woman 18 months post chemo-radiotherapy for cervical cancer]

"I suppose sexual intimacy it's eh....so I'm nine years older than [partner's name]. I think one's sexual appetite runs its normal course and so it was, ehm, very infrequent, I suppose infrequent anyway."

[PTNR05: >60 year old man living with PT21, a 54 year old woman 18 months post chemo-radiotherapy for cervical cancer]

It was also interesting to note that in the months prior to confirmation of a cancer diagnosis, two of the women commented that they were aware of pelvic symptoms such as excessive post-coital bleeding (PT04) and difficulty in achieving normal penile penetration because of the presence of a pelvic 'lump' (PT07) that had already impacted on sexual activity prior to any treatment induced effects.

Six of the women who took part in the interviews felt that there were really no obvious changes in their sex lives after treatment completion. This appeared to be particularly the case among couples where sexual intercourse was relatively infrequent and / or less important within their relationship as illustrated by the following extracts.

"I wouldn't say that we have any particular [sexual] problems.....I'd say it's just that, it's the usual, you're tired or you've been working, you know, nothing in particular different." [PT05: 36 year old woman 12 months post chemo-radiotherapy for cervical cancer]

"I didn't have pain or discomfort. It didn't really bother me that, you know, like I wasn't frightened, nor was I expecting anything greater than what is the normal sexual activity. That is why I don't....I am not really much affected." [PT18: 46 year old woman 6 months post surgery / radiotherapy for endometrial cancer]
"Yes but it's [sex] not been, it never has been the biggest thing, so I don't think it's not to me like a loss in a way...I feel comfortable with it, I don't feel uncomfortable with it, I don't feel guilt and I don't feel I have lost anything..."

[PT21:54 year old woman 18 months post chemo-radiotherapy for cervical cancer]

This diversity in women's sexual lives illustrates the importance of baseline knowledge of the woman and couple's pre-illness sexual and relationship norms so that any changes occurring post-treatment can be placed within an individual and / or couple context and the meaning of any altered sexual life can be more accurately assessed.

Figure 8.1: Data categories and sub-categories: Living with a changed sexual life after cancer

Figure 8.1 provides a summary of the data sub-categories contributing to this category. Although initial coding led to the identification of masturbation as a separate data code, this was subsequently incorporated within the specific sub-category that this sexual behaviour related to. Thus, for example, if a single woman spoke of reduced frequency of masturbation because of changes in her level of sexual desire then this data extract would be placed under loss of sexual desire and arousal difficulties, whereas if masturbation led
the woman to realise her orgasm had changed this would be placed in the category changes in orgasm.

8.1 Fear of resuming sexual intercourse

Anxiety associated with resumption of sexual intercourse after treatment had completed was a common experience, directly mentioned by fifteen out of the twenty-four women interviewed. Awareness of this fear was specifically mentioned in only two health professional interviews with one radiotherapy nurse (HCP11) and one therapy radiographer (HCP16). A common anxiety expressed by the women was fear of causing internal damage as a result of having intercourse.

"I think that once you've had your check up like anything, once you know, you have had as far as you can an all clear then I think you are happier to think, well then it's all healed up down there, it's alright. You know, because I think from the physical side you need to know that before the mental bit comes in" [PT06: 72 year old woman 12 months post surgery/radiotherapy for endometrial cancer]

"I think, you know, to begin with I suppose I was concerned about my anatomy, I was concerned about breaking something, you know, tearing something, damaging something...so ehm, you know, to begin with I felt like that every single time. And I was thinking 'Oh my God' you know, it's awful, well not awful, I was just anxious and as time went on I became less anxious." [PT09: 50 year old woman 12 months post chemo-radiotherapy / A-P resection for rectal cancer]

A few of the women had specific fears arising from their pre-illness experience of cancer symptoms, particularly in relation to the possibility of post-coital bleeding, and would avoid sexual intercourse for that reason:

"...it's funny how your mind can take over your self, so then when it [treatment] was all finished I did try it [intercourse] a couple of times but I was really dubious, you know, and as the months passed it wasn't good sex because in my mind, as I say to you, I think I was half to blame with this, to be honest with you, because it's in my mind that I was frightened I was going to see blood.
Researcher: What wasn't good about it?
PT04: Because I was frightened to let him put it [his penis] fully in. [Researcher: Right] I'm frightened of seeing blood again and I'm still like it." [PT04: 64 year old woman, 8 months post chemo-radiotherapy for cervical cancer]
"I suppose a lot of how I felt about this is because the first symptoms were of course after I had sexual intercourse, bleeding, and therefore in a way my mind associates this a little bit with it. The symptom that I’m always looking for….And I think in the same way, that is why I feel intercourse would not, it would just be, it wouldn’t be enjoyable for anybody to have it because to me it would be something that I would be looking for all the time, gosh, you know, is that alright, is that not alright and therefore you can’t actually forget it.” [PT21:54 year old woman 18 months post chemo-radiotherapy for cervical cancer]

Concerns were also expressed about experiencing sexual pain, discussed in more detail later in this chapter, or fear that sex would simply feel different as a result of the treatment women had endured.

“But we didn’t actually, he wasn’t really penetrating me for a little while afterwards because it was hurting and he was trying and ehm, he just said ‘No, I’m not going to hurt you like this’ and so we didn’t [have sex]. So it took many months for me to be courageous to say, just go for it, its got to hurt for a while.” [PT19: 62 year old woman 17 months post surgery/radiotherapy for endometrial cancer]

“I didn’t think I’d be left feeling like this about sex, the fear of it and how uncomfortable it is. I didn’t expect that.” [PT22: 51 year old woman 31 months post surgery/radiotherapy for cervical cancer]

"PT12: Within a month of stopping the treatment it [sexual interest] came back and that was probably the most difficult time actually, the thought of actually resuming a sexual relationship again was actually more difficult because having been without it for so long, I’d kind of almost adjusted to it in a way [laughter].

Researcher: And presumably that was linked with anxiety about what it might be like when you did resume sex again?
PT12: Yeh, I think so because, like, the physical discomfort and actually wondering at some point, you know, I did wonder am I ever going to feel that way again. Will I have an orgasm again? You know those sorts of things. So I think part of me was probably blocking having to face it really.” [PT12:42 year old woman 14 months post chemo-radiotherapy for cervical cancer]

For some women the fear of being sexual with their partner related to treatment late effects that led to them having reduced control over their bowel or bladder function. They were therefore reluctant to engage in sexual intercourse for fear of being incontinent.

“I have a definite problem with, ehm, wetting the bed when we have sex, ehm, which is a real blinking nuisance , ehm, and so that inhibits me. I just say to my husband stay away from me. But I’m working on it with, ehm, I’m doing all my pelvic floor exercises.” [PT24: 54 year old woman 12 months post chemo-radiotherapy / anterior resection for rectal cancer]
"The fact that it [tumour] was all in that area I just didn’t want to know. And after the, oh, that was something I wanted to say, after the reversal [of temporary colostomy] I didn’t have terribly good control. If I passed wind I never knew what else was going to come through and that was very inhibiting, very inhibiting. So that put me off [sex] for a while, but actually it’s got, you know, its pretty good now."

[PT10: 68 year old woman 24 months post radiotherapy / anterior resection for rectal cancer]

A smaller number of women held myths about the potential link between sexual activity and cancer or radiation and voiced fears that sexual intercourse may make their cancer return or that they could pass on radiation to their partner by sharing a bed. These concerns led to a number of women avoiding sexual intercourse with their partner.

".....knowing I have had a tumour there and knowing it has gone, touch wood. It’s just the thought that maybe having sex could do some damage and bring it back, I don’t know. Strange!" [PT02: 51 year old woman 12 months post chemo-radiotherapy for anal cancer]

"Ehm, I remember at Christmas after the first week [of radiation treatment], so it was all new, feeling a bit unsure of my health stage. I asked and I said look is [partner’s name] at any risk if we are sleeping together? I mean literally in the same bed because sex was not on our minds at that stage." [PT 23: 58 year old woman 29 months post chemo-radiotherapy for anal cancer]

"I’m very nervous of any movement down there as well could cause things to activate again, yeh I think that’s it really.....Because sometimes obviously there is that need [to be sexual] and ehm, I have climaxed but I’m just nervous of stimulating anything in that area, ehm, that could start, I don’t know, cells growing again in the wrong way. I don’t know what’s at the back of my mind really when I really come down to it. Yeh, I suppose it is the thought, just the thought of, you know, this could trip something again and you know, you can live without this [sex] really, you know, why put yourself on the line again. I think that’s it really." [PT22: 51 year old woman 31 months post surgery / radiotherapy for cervical cancer]

This woman (PT22) had a personal theory or attribution in relation to her experience of cancer whereby she believed that cancer development could be “tripped” by certain circumstances or behaviours. Her interview extract also appears to contain a family belief taken from her mother that she had “tripped” something originally in order for her cancer to develop. I made this lady aware that we would come back to this disease attribution after her interview concluded as it concerned me that she was avoiding sexual contact with her husband at least in part because she felt having sex again was dangerous and could directly cause her cancer to recur.
One clinical nurse specialist in gynae-oncology from the health professional interviewees specifically mentioned sexual myths as an aspect of patient education she routinely covered in discussions with women.

"HCP09: And it's also the misconceptions as well. You know, to make sure you've covered all aspects of the misconceptions.
Researcher: Such as, can you give me some examples?
HCP09: Oh I mean, you know, the classic ones I suppose are things about, things being contagious, about radiation being passed on."

Women who were single at the time of their cancer treatment, or whose relationships had ended around that time, voiced concern about whether or not they would have the self-confidence to establish a new sexual relationship.

"It does mean that, you know, I am in some degree of fear about any potential sexual relationship or possibilities of a sexual relationship. And what worries me is that I will sub-consciously avoid it because it frightens me." [PT03: 55 year old woman, 8 months post surgery/radiotherapy for endometrial cancer]

"PT08: In fact I mean after forty years, I know it sounds ridiculous, but I'd gone off the idea [of sex] with him anyway for lots of reasons. But I'd like to think I'd meet somebody and it would all happen but whether I'd have the confidence is another thing.
Researcher: How do you think you will broach the ability to be sexual again with another man that you find attractive?
PT08: God, I think I'd have to have a tub of vodka first!" [PT08: 58 year old woman 6 months post chemo-radiotherapy for anal cancer]

These extracts illustrate the considerable fear and anxiety experienced by women in resuming their sexual relationships after cancer. While for some this anxiety was overcome, for others the fear associated with sexual activity persisted and in some instances led to sexual avoidance. Few of the women interviewed appeared to have expressed these fears to a member of their health care team and it is uncertain whether or not they viewed such concerns as legitimate to address within oncology follow up. On conclusion of the majority of interviews, particularly those that took place in the women's own homes, they spoke about how taking part in the study had been one of the few opportunities they had experienced where they could talk in depth about what having cancer had meant for their relationship and sexual well-being.
8.2 Coming to terms with an altered sexual identity

Within the interviews there were both overt and covert examples where women's sense of femininity and sexual identity had been adversely affected by both direct and indirect treatment effects. For some these were temporary effects, while for others altered appearance and/or function was a permanent change that women and their partners endeavoured to accommodate within their lives.

Changes in femininity and sexual identity were brought about by a diverse range of treatment effects and included psychological responses to the vaginal changes women had experienced as a result of surgery or radiotherapy (see section 7.4.3).

"...emotionally I feel my womanhood's been wrecked. It's totally.....nuclear war has gone off down there!" [PT01: 45 year old woman 21 months post chemo-radiotherapy for cervical cancer]

One of the women (PT03) who had undergone surgery and radiotherapy for endometrial cancer had found her experience of vaginal brachytherapy particularly harrowing and said that vaginal changes caused by her treatment had left her feeling "...completely de-sexed by the whole thing".

The women's sense of femininity was also affected by changes in external appearance that were hidden to all but the woman's intimate partner, such as radiation induced changes in skin texture, colour and pubic hair loss. This was commented on particularly by the women treated for anal or rectal malignancies.

"Researcher: In what way has it [treatment] changed the way you think of yourself as a woman, if any?
PT08: Ehmm, I feel a bit, this might sound daft, disfigured.
Researcher: Do you?
PT08: The fact that I'm practically bald. And the skin is a bit on the dry side. So I, I feel disfigured. I think that's the best way to describe it.
Researcher: So that loss of pubic hair and the fact that your skin is so delicate has really changed the way you see yourself?
PT08: Yeh. So I almost feel a bit disabled.....disfigured!" [PT08: 58 year old woman 6 months post chemo-radiotherapy for anal cancer]

"PT10: One thing that bothered me, they told me I'd lose my pubic hair. Would that bother you? And I said no, but it did. I really didn't like that....Mmmm I really didn't like that!

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Researcher: What was it do you think that made you feel uncomfortable about that?
PT10: There's a, there's a big mirror on our wardrobe [the doors] they slide across and that was the only time I would actually...it was the sight of it. I felt naked (laughing).” [PT10: 68 year old woman 24 months post radiotherapy / surgery for rectal cancer]

“PT23: There's nothing else you can say about it [vulval and perineal skin changes]. And it is distressing because, you know.....you like to think of yourself as being.....I feel very unfeminine.
Researcher: Do you?
PT23: Because it's ugly, the pubes are struggling, you know, couldn't believe it!
Researcher: Did the pubic hair grow back or in little fits and starts?
PT23: It sort of......token, but the tissue on top of the pubic bone apparently in some people it's a lot worse, but it's very ugly. Because I made a big mistake at the weekend; riding a bicycle with this kind of tissue is not on!” [PT23: 58 year old woman 29 months post chemo-radiotherapy for anal cancer]

This lady (PT23) spoke of the “red square” skin discolouration she was aware of as demarcation of her treatment field and of the way in which the unpredictability of pain in her perineum and peri-anal region led to a changed perception of her bottom whereby she experienced this part of her body as being out of adult control, leaving her feeling that she had become a “big baby”.

“Just being uncomfortable is one of my biggest gripes, you know, and [partner’s name] is such a sweetie ‘Oh my bottom hurts’ And he does understand and I feel like walking around with my legs like a duck. Bottom sticking out because it is uncomfortable walking.......And I have not come across something that is soothing and calming. I mean [surgeon’s name] has given me these suppositories I can use but when the bottom is unhappy it is uncomfortable even to put the bloody suppository in! It is just terribly, terribly uncomfortable and feeling like a big baby!”

It was remarkable that this lady was over two years post-treatment at the time of her interview and still experienced the consequences of severe radiation tissue changes in her vagina, perineum and peri-anal region that required surgery to ameliorate vaginal occlusion and anti-inflammatory drugs for her chronic skin and subcutaneous tissue changes. This lady's narrative also illustrates how functional changes and chronic pain can contribute to altered self-image.

Perhaps a less common experience was that of PT24 who kept her husband at arm’s length when he wanted to be intimate with her because “…I used to be able to smell the
chemotherapy on my skin.” She also spoke about changes in bowel function that made her feel “dirty” and less sexually attractive to her partner.

“And because of having the runs and everything I always felt like I was dirty. Terrible haemorrhoids and shocking diarrhoea and so all that doesn't really add for a good sexual feeling. No, and I was always very aware of the smells and things so, you know, trying to keep myself clean I was always in the bath.”

[PT24: 54 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

This woman had to endure both the indignity of loss of bowel control as a result of her chemo-radiotherapy followed by further sexual inhibition caused by a temporary colostomy for six months associated with her subsequent surgical treatment.

“He said it didn't worry him, the stoma, but I was definitely put off [sex] by the stoma. Ehm, I used my tops, you know, the little camisoles, I used to put camisoles around me so that it would keep it [stoma bag] in place.....and so he couldn't see it [stoma] and then, and we did make love then but probably missed many times, not very often.” [PT24]

Of the four women with rectal cancer who took part in the study, two had a temporary colostomy (PTs10 and 24) that was reversed after six months and the remaining two women (PTs 07 and 09) had a permanent bowel stoma. All of these women commented on the negative impact of a stoma on their sexual confidence and identity and this was endorsed by comments from two of the women's partners (PTNRs 01 and 02)

“And to be told that, sort of immediately, that the type of cancer I had, that I would have to have a stoma and it was going to be irreversible, and I mean at the time to me that was just the most horrendous thing. I just thought to myself well, he's never going to find me attractive ever again with a bag stuck on the front of me. And I thought I'd have to wear smocks all the time and, you know, I would look terrible and that he would, you know, go off and leave me or something.” [PT09]

“[Wife's name]'s biggest fear [was] that I would find her unattractive due to the fact she had a colostomy, but for me that was irrelevant. Ehm, but then, and this occurred just around the end of the year [husband developed erectile dysfunction]. I found myself in a position and continue to do so whereby, you know, I can ehm get excited, I can penetrate, but I can't maintain [an erection].”

[PTNR01: 41-50 year old man married to PT09: 50 year old woman 12 months post chemo-radiotherapy and A-P resection for rectal cancer]

Both of the women with temporary stomas resumed sexual intercourse but had experienced loss of sexual desire (PT10) and dyspareunia (PT24) while PT07 had
developed vaginal stenosis and neither dilation nor sexual intercourse had been possible since her surgery 12 months previously. Although PT09 and her partner had resumed their sexual relationship without much difficulty after initial anxiety was overcome, this lady’s husband was now experiencing erectile dysfunction that he associated with the strain of his wife’s illness on their relationship. Only PT09 could recall her consultant oncologist (HCP08) asking her direct questions about the resumption of sexual intercourse, but there was no awareness that the couple were now experiencing sexual difficulties as a result of her partner’s erectile dysfunction. None of the remaining three women had been asked about their sexual recovery during their regular follow-up clinic visits every three months.

Among the five partners interviewed there was concordance between three of the women’s accounts of altered self-concept and that of their partners, demonstrating a strong sense of empathy in these couples (PT09/PTNR01; PT10/PTNR02; PT21/PTNR05). The impact of sexual changes on women’s partners is discussed further in section 8.8.

8.3 Coping with treatment induced menopause

In addition to changes in sexual function, identity and femininity, a number of women in the study also faced the changes associated with a medically induced menopause that would create both physical effects and psychological responses to this altered status and new life stage. Of the 24 women who were interviewed for this study eight were pre-menopausal at the time of their treatment and a further three women were peri-menopausal with early signs of menopause.

The influence of menopause on female sexuality is an important one as the hormonal changes associated with this life transition create specific symptoms, such as vaginal dryness and lowering of sexual desire, that impact negatively on the sexual well-being of women. Women whose menopause is induced by surgery or pelvic radiotherapy can be expected to undergo sudden ovarian failure and rapid hormonal changes and as a result many women experience more severe menopausal symptoms than if they were going through a natural menopause. Furthermore, in western cultures at least, the transition to menopausal status is one normally associated with cessation of reproductive capacity and a decline in feminity and sexuality. As a result one might expect negative psychological responses from women who are forced to enter this life stage at an earlier
time than would have occurred naturally. The impact of menopause and loss of reproductive capacity is also alluded to in section 7.3.1 in exploring factors that contribute to popular constructions of sexuality in older women as individuals and in wider society.

As can be seen from table 8.1, with the exception of two pre-menopausal women treated for cervical cancer, all eligible women had hormone replacement therapy (HRT) recommended by their treatment team. Where HRT was contraindicated the women either had endometrial cancer (PTs 03, 18), a hormone responsive malignancy or, as in PT02, the contraindication of a familial history of breast cancer.

Table 8.1: Patterns of Menopause Management

<table>
<thead>
<tr>
<th>Participant Demographic Details</th>
<th>HRT Recommended</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pre-Menopausal Women</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PT01: Cervix (43)</td>
<td>No</td>
<td>Plans to discuss HRT with GP</td>
</tr>
<tr>
<td>PT05: Cervix (35)</td>
<td>Yes</td>
<td>Non-pharmacological management agreed with GP</td>
</tr>
<tr>
<td>PT09: Rectum (49)</td>
<td>Yes</td>
<td>Plans to discuss HRT with GP</td>
</tr>
<tr>
<td>PT12: Cervix (41)</td>
<td>No</td>
<td>Hormone responsive tumour</td>
</tr>
<tr>
<td>PT13: Cervix (31)</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>PT18: Endometrium (45)</td>
<td>Contraindicated</td>
<td></td>
</tr>
<tr>
<td>PT20: Cervix (31)</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>PT22: Cervix (48)</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td><strong>Peri-Menopausal Women</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PT02: Anus (50)</td>
<td>Contraindicated</td>
<td>Familial breast cancer history</td>
</tr>
<tr>
<td>PT03: Endometrium (54)</td>
<td>Contraindicated</td>
<td>Existing HRT stopped at diagnosis: hormone responsive tumour</td>
</tr>
<tr>
<td>PT24: Rectum (53)</td>
<td>No</td>
<td>No request made by patient</td>
</tr>
</tbody>
</table>

While most of the women had only considered HRT to resolve their menopausal symptoms, two of the women stated a preference for complementary therapies or exercise, with PT09's GP recommending these measures as a positive alternative to conventional medication.

"At that time I thought it [fatigue] was maybe hormonal and said to [consultant], you know, can I go on HRT or something? And she said well it's not up to me to prescribe it but there's no medical reason why you can't. So go and speak to your GP. And she has been my GP for fifteen years and she's the same age as me and she's seen me and my family through thick and thin and I respect her judgement, you know, totally. And she just said to me well I just don't think its [HRT] a good idea for you. You manage so well with running and all the sort of physical activities you do and I'd much prefer you go and try Black Cohosh and these alternative
remedies and you eat a healthy diet, you know, just get yourself back into doing a bit of exercise and you'll be OK sort of thing.....I have night sweats, I have the occasional hot flush but nothing that's not controllable really. And my energy has come back again, so now I think it probably wasn't hormonal it was probably the chemotherapy.” [PT09: 50 year old woman, 12 months post chemo-radiotherapy for rectal cancer]

“I started reading some literature, because I was aware from the stuff [CNS] had given me that there was going to be some quite dramatic changes in my body.....I wanted, and I talked to some older female friends who had gone through the menopause and used HRT as well, so I talked to them.....but I've kind of pushed it under the carpet again and it keeps resurrecting itself because it's there and it is having a big impact on me now. And I'm planning to go to see my GP shortly to talk about it, but I wanted, I wasn't ever thinking about going down the HRT route, I wanted to try to deal with it through change in my diet, my lifestyle, looking at alternative remedies like homeopathy and things. I really didn’t want to look at both, I guess at that particular time there was a lot of stuff coming out about HRT.” [PT12: 42 year old woman, 14 months post chemo-radiotherapy for cervical cancer]

This lady (PT12) had not yet taken any definitive action in relation to the management of her menopausal symptoms, perhaps because coping with menopausal symptoms was only one aspect of a number of changes that needed to be accommodated in her recovery after cancer.

Analysis of the women’s transcripts revealed that a number of women experienced disruptive menopausal symptoms before discussing HRT provision with their treatment team or GPs and, as illustrated by participants PT01 and PT12, at times it was the women themselves who initiated discussion about menopause management.

Aside from discussing menopause as a consequence of treatment induced ovarian failure at the time of informed consent before treatment, this topic did not appear to be regularly discussed by health care professionals during follow-up. This lack of focus on menopause management was also seen in participant observation data whereby menopause was only mentioned in seven out of 30 consultations where the woman was menopausal as a direct result of her cancer therapy (section 5.2).

The women talked about a number of symptoms associated with treatment induced menopause including a lack of energy, joint aches and pains and weight gain but particularly noticed a reduction in their sexual desire.

“I feel I've got fat because of the menopause which is, you know, the other side effect. I need to get some HRT because my hips are a bit rickety and stuff like
that....my desire has definitely dropped off, which I assume is because of the menopause, so I suppose the HRT might help that a bit?" [PT01: 45 year old woman 21 months post chemo-radiotherapy for cervical cancer]

“I got no interest [in sex] whatsoever, it's gone dead! I don't know whether it's because I am going through the change, or what?” [PT02: 51 year old woman 12 months post chemo-radiotherapy for anal cancer]

“I think give me another six months and I should be pretty much back to normal, although my sexual drive is definitely low, but I think it would be anyway. With going through the menopause...And I'm pretty much, I think I'm pretty much through the menopause, all my hot flushes and that have just about gone and I'm feeling much, much better.” [PT24: 54 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

It was interesting to note that PT01 had not yet sought HRT from her GP despite experiencing menopausal symptoms at 21 months post treatment completion.

One of the women (PT13) in the study had been receiving HRT for approximately 12 of the 16 months following treatment completion and had hoped this medication would improve her complete lack of sexual interest. A reason given for her participation in the study was that in the absence of any improvement in her sexual desire and associated sexual and relationship difficulties she hoped I would be able to give her some guidance about what she could do to change her sexual well-being in this respect.

“PT13: I'm having this hormone replacement therapy, but I have been having it for some time now. It's almost a year, or maybe well over a year. I have been hoping that it will probably change things...I was hoping that I would get better but there is nothing, no change. And I wouldn't mind talking about it to somebody to see if they could help me in some other ways, other than the HRT.

Researcher: Okay, well at the end of the interview what I will do is I will talk you through some of the options that are available within this hospital and beyond the hospital so that you can make some choices about whether or not you would like to take this further.” [PT13: 32 year old woman, 16 months post chemo-radiotherapy for cervical cancer]

The wider impact of illness and treatment on women’s sexual desire is discussed in more detail in the next section.

8.4 Loss of sexual desire and arousal difficulties

In contrast to men where the desire and arousal phases of their sexual response may be viewed as being more distinct, the women in this study often talked about changes in their
sexual interest and altered patterns of sexual arousal as elements of the same phase. Women identified changes in the thoughts and feelings they associated with sexual expression together with observed physical changes (or the lack thereof) in their vagina and genital area.

What was interesting to note was the extent to which women spoke of their sexual desire in terms more commonly associated with male sexual desire patterns, expressing a belief that they should experience an innate interest in or desire for sex arising from within themselves. This contrasts with the model of female sexual desire more recently suggested by Basson (2000) whereby female sexual desire is more often experienced as a responsive desire that builds following a welcomed approach from the woman's sexual partner.

Two nurses (one gastro-intestinal cancer CNS and one outpatient staff nurse) were the only health care professionals who spoke about their experiences of working with women who had approached them complaining of reduced sexual desire after cancer treatment.

"She had lost all interest, you know, she said I'd rather he just didn't ask it [sex] of me, but felt she had to talk to somebody because he [woman's partner] felt that she'd finished treatment, had her surgery and six months down the line he wanted sex. And she said, I mean just chatting to her, long before her problem [cancer] she had gone off sex. They both had busy lives, she could use that as an excuse, I'm tired, now she was at home all the time, she'd given up work and so it was those issues you know, it [sex] was not really her need."

[HCP10: Clinical nurse specialist in gastro-intestinal cancer]

"So you talk to them about these things and they say, oh they lost interest, and you try to persuade them, if you can, that that's [loss of sexual desire] not the end of the world."

[HCP15: Outpatient department staff nurse]

It is not clear from these brief extracts whether these practitioners felt confident in responding in practical or emotional terms to women's expressed concern regarding their lack of sexual desire after treatment.

Despite the prevalence of loss of desire in response to direct questions (Q.9, appendix 15) in women's interviews, this topic was an infrequent aspect of female sexual morbidity discussed during follow-up clinics as noted in figure 5.3. One of the women had interpreted the lack of enquiry during follow up about loss of sexual interest to mean that this change must be considered "just a normal thing" and so did not believe it was something she should enquire about. This illustrates the point that where enquiry about
sexual changes post-treatment is not made by health professionals, women may assume that this is either an expected side effect of their treatment or is not a legitimate question to ask of their treatment team.

"Researcher: Do you still think about having sex, do you still have an interest in being sexual with him [woman's husband]?
PT07: Not at the moment, no. No I must admit its [sex] not sort of crossed me mind. Well no, because I thought perhaps it was just a normal thing, you know, perhaps it was just normal that, ehm, you just sort of go off sex for a little while and, you know, and it'll come back or whatever. And it never really entered my head to ask anybody. As you say, no-one asked me about it so I didn't even bother to ask anyone about it so, yeh." [PT07: 63 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

This extract also illustrates that women do not always know what is considered “normal” in their sexual recovery post-treatment. It would seem entirely reasonable to assume a temporary loss of sexual desire is a normal response to serious illness but the question would remain as to whether or not protracted low desire is a clinical problem worthy of enquiry during routine cancer follow-up.

Women attributed the reduction in their sexual interest to a number of psychological and physiological changes associated with their experience of both cancer and its treatment. Their attributions ranged from fear of post-coital bleeding (PT04), fear that sex could cause recurrence of their cancer (PT02, PT22) to menopause (PT01), fatigue and stress of illness (PT06) or a changed self-image (PT09, PT10).

"PT02: But I seem to have lost my sexuality. I don't even get, I don't know, it [sexual desire] seems to have gone. It's like you've gone from sexual relationship to going frigid, I don't know.
Researcher: So what would you put that down to, why do you feel so different?
PT02: I suppose fear, fear of it coming back, or you know, having sex might start something off, I don't know." [PT02: 51 year old woman 12 months post chemo-radiotherapy for anal cancer]

"Researcher: Did you find that you were still interested in sex or were you just very preoccupied with your illness?
PT06: No, but I think basically I think you are tired. Yeh and living day to day, I mean the worry is always there..." [PT06: 72 year old woman 12 months post surgery/radiotherapy for endometrial cancer]

"Researcher: It sounds as if your desire to have sex with your husband didn't really alter, or if it did it only dipped temporarily?
PT09: Yeh, I would say so, I would say so. And mostly it was, it was my reluctance and all to do with, you know, the physical appearance or replumbing as I like to call it, you know." [PT09: 50 year old woman 12 months post chemo-radiotherapy/ surgery for rectal cancer]
For some women and partners there was no perceptible difference in their desire for sexual contact before and after cancer treatment. This appeared to be particularly the case among couples who considered their “drive” or desire for sexual expression to be lower than average as a personal norm and accepted as such within their relationship.

“Researcher: Would you say there’s been any change in your sexual life together after your radiotherapy?
PT18: To be honest, you know, I didn’t have that kind of desire, you know, number one.” [PT18: 46 year old woman 6 months post surgery / radiotherapy for endometrial cancer]

“I think it’s just something which [patient name] has not, in the ongoing saga of having to lubricate and then, I think it’s just killed that [sexual interest] which doesn’t seem unreasonable. Perhaps the state of my libido is not a, I can’t say it’s a major problem. Perhaps I wouldn’t be worried the other way, being married to a much younger woman whether in fact my, my appetite might have failed before hers. Its [levels of sexual desire in couple] probably come fairly even as a result.” [PTNR05: >60 year old partner of PT21, 54 year old woman 18 months post chemo-radiotherapy for cervical cancer]

This appeared to be an example of personal variance, perhaps based on a lower level of sexual desire in the male partner, and not necessarily related to age as there were a number of older women in the study who remained sexually active on a regular basis and continued to experience a responsive desire for sexual contact with their partner.

Some women who were not in a current relationship implied that the absence of a partner meant they were less concerned about having no or low sexual desire because there was no personal guilt or expectation coming from themselves or from needs expressed by a partner with intact desire.

“Not so much [sexual desire], not since the treatment. I mean before that it used to get to be a desperation thinking, ‘Oh god, am I that unattractive’ you know, where am I going wrong sort of thing. But ehm now I mean if I do get a kind of urge, want for a better word, I suppose, its not a huge problem, you know. I don’t get, I don’t worry about it. It would be nice to have those feelings back and to feel wanted and whatever but no, I don’t worry about it.” [PT08: 58 year old woman, 6 months post chemo-radiotherapy for anal cancer]

While other women continued to engage in masturbation to fulfil a personal outlet for sexual feelings.

“Just after my treatment I still had sexual desire so I would masturbate as and when, you know, not very often but occasionally. But I think as my hormone levels
dropped, now I'm menopausal I mean I assume that's the reason for it. Very rarely so and my desire has definitely dropped off....and I don't feel, you know, like if I was with someone I'd be wanting sex but obviously I'm by myself....” [PT01: 45 year old woman 21 months post chemo-radiotherapy for cervical cancer]

The level of personal distress or negative emotions experienced by women regarding this change appeared to vary according to the personal meaning they attributed to loss of desire, their relationship circumstances and the extent to which they felt guilty that in having no desire for intercourse they may be depriving their partner of a sexual outlet.

"I mean I was trying to think whether I didn't find that [loss of desire] too distressing in a way. I mean I was prepared for it to happen so when it did start I think I remember feeling a bit upset for a couple of days and kind of like crying about it. But in relation to everything else that I was feeling it kind of didn't stand up there as a big issue for me. In a way it was slightly a relief because I didn't want to have to even think about or cope with having sex. So the fact that I didn't even feel the urge or need for it [sex] in any way was almost like taking away the responsibility of having to deal with it. I felt completely numb; there was just no sexual feeling whatsoever.” [PT12: 42 year old woman 14 months post chemo-radiotherapy for cervical cancer]

"Researcher: What about your partner. If I was to ask him about how you'd changed since your treatment what do you think he'd say?
PT02: More and likely he'd say 'she don't come near me'. But we just don't talk. Don't cuddle, don't kiss, don't talk, don't do nothing. It's strange.
Researcher: Has he made any approaches to you?
PT02: He has dropped hints. And I've just ignored them. Terrible, really!"
[PT02: 51 year old woman 12 months post chemo-radiotherapy for anal cancer]

For some women this sense of guilt or obligation was so strong that they would engage in sexual behaviour in order to meet their partner's perceived sexual needs.

"I think there was slightly less interest there. But I didn't give in to that because it wasn't fair to him. He was being good to me so ehm, but it wasn't something, I didn't feel put off by it at all. There just wasn't as much interest but then once we started [having sex] maybe it was ok.” [PT19: 62 year old woman 17 months post surgery/radiotherapy for endometrial cancer]

"No interest at all. So we made sex other ways, but very seldom. It was very seldom. Because I used to start feeling guilty when it was getting up to about a month and I thought aw, so I used to try and look after him somewhere about every, once a month, you know....we previously to that [cancer treatment] it was at least once a week. And it had got to the point I didn't want him touching me. What was I, 53 or 54 at the time and I thought it was too young really to lose completely,
any libido at all, you know, you've got no sexual desires...I thought that's the end of it [her sexual life] I think I got a bit depressed about it."

[PT24: 54 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

Other women spoke of a marked reduction in both their desire to engage sexually with their partner and of difficulties in becoming sufficiently aroused to reach orgasm and felt they were not responding sexually as they had done prior to their illness.

"PT20: Because of everything that's happened.....and also I don't get the feelings like I used to.
Researcher: Right. So you don't feel as aroused or as interested in sex?
PT20: No.
Researcher: So if he [partner] was to make an approach to be intimate or sexual with you how would you respond?
PT20: I'd feel how I was before but I'd hope that, you know, he could see that I'm satisfied as much as I used to be, which I'm not, so you know....I mean because I haven't got that high a sex drive anymore, you know." [PT20: 33 year old woman 22 months post chemo-radiotherapy for cervical cancer]

This woman and her partner had attended psychosexual counselling after her treatment had completed as her partner had developed erectile difficulties and the couple had been avoiding sexual contact as a way of reducing the distress it had caused between them. The couple attributed his erectile dysfunction to a stressful and busy job and did not relate their sexual difficulties to her reduced sexual desire, altered sexual arousal and reduced sexual satisfaction following cancer treatment.

"Researcher: And when you think about the times you made love to your boyfriend did you find it as easy to get aroused as before you were ill?
PT20: It wasn't as easy, but it was even harder afterwards. But I felt, it was funny because I felt, you know, like sometimes when you, any time you feel a tingling and I just don't get anything like that at all, no. I have been [aroused] recently but not as often. Maybe it could be once a month or not even that, when I feel a bit aroused, whereas before it was a lot more.....I have got a vibrator that I use. Yeh, I don't insert it inside but I just....(Researcher: Use it on the clitoris) Yeh, and before that used to arouse me quite quickly but now it takes ages. So sometimes I don't use it because....but I still think, you know, it's going to take a while yet for things to go back to normal so I'm not worried about it really." [PT20: 33 year old woman 22 months post chemo-radiotherapy for cervical cancer]

As with PT07 this woman believed that the sexual changes she had noticed following her treatment could still return to her pre-illness norm and so she was not unduly concerned
about them and had not sought any information about sexual recovery from her treatment team.

8.5 Changes in orgasm

Orgasm was not a phase of women’s sexual response that was discussed during observed follow up consultations (section 5.3.) as the focus regarding sexual recovery post-treatment was to ensure future feasibility of intercourse as opposed to exploring the aspects of human sexual response that relate to women’s sexual enjoyment or satisfaction. This omission occurred despite the fact that changes in orgasmic sensation and reduced sexual satisfaction were identified in the literature as changes that can arise from pelvic cancer treatment.

Through direct questioning a number of women interviewed claimed to have noticed changes in the sensation of orgasm experienced. In the main, women experienced their orgasm as being less intense or less satisfying and while for some this was a temporary change, for others it had persisted.

"Researcher: And when you masturbate did you find that your orgasm had altered at all?
PT01: Yes, yes, yes, yes!
Researcher: In what way was it different, do you remember?
PT01: Ehm, not as satisfying I suppose is the word.....not as......not the same and not....is this sort of a, a technical thing, because it definitely is different.
Researcher: Some women say it doesn't feel as intense.
PT01: Yes! Instead of five things happening there would be one or two things happening, two layers instead of five layers, I don't know how you [describe it]. But yeh, definitely, so it's less worth doing." [PT01: 45 year old woman 21 months post chemo-radiotherapy for cervical cancer]

"PT10: And I can still climax so, you know, it all works.
Researcher: And when you climax has your climax changed at all since your treatment or is it just the same?
PT10: I can climax better from clitoris stimulation.
Researcher: Yes. It's no less intense a feeling, for example?
PT10: No. It was to start with actually. The clitoris didn't have as much feeling and I thought, 'Oh my goodness, what have they done to me?' But it came back...it's absolutely back to normal." [PT10: 68 year old woman 24 months post radiotherapy / surgery for rectal cancer]
Other women were aware of the increased time taken to achieve orgasm or that it was no longer possible to achieve orgasm on each occasion when they either masturbated or had sexual contact with a partner.

"Researcher: And when you think of your orgasm, for example, is your orgasm the same as it was before or has it changed? 
PT20: It takes ages. Yeh, I mean it's funny because I feel like something is happening but nothing does happen." [PT20: 33 year old woman 22 months post chemo-radiotherapy for cervical cancer]

"Researcher: Are you still able to achieve orgasm after or during sex? 
PT13: Rarely, it's not as it was before." [PT13: 32 year old woman 16 months post surgery / chemo-radiotherapy for cervical cancer]

"Researcher: What do you think about your own climax and your ability to get aroused? Have they changed at all since your treatment? 
PT19: Yes. I don't think it’s always quite as easy to climax. Yeh, I've had difficulty on a couple, on a few occasions, but not always, on a few occasions. 
Researcher: And what do you put that down to? 
PT19: I think I've just accepted the fact that it's possibly a side effect of the therapy I had." [PT19: 62 year old woman 17 months post surgery / radiotherapy for endometrial cancer]

One woman spoke in detail about altered orgasm as a result of no longer having a uterus to contribute to her orgasmic sensation following hysterectomy for endometrial cancer.

"Researcher: And in terms of having an orgasm has that felt the same as before? 
PT14: That feels different. Even when I masturbate my orgasm feels different. 
Researcher: In what way do you think it feels different? 
PT14: Normally when you have your nipples stimulated, obviously it's a first and then start stimulating round the clitoral area and you can feel, and I always feel the womb moves up when you're getting, you know, sort of near it [orgasm], and you can feel these sensations. And its not there and I don't know, well I haven't got a womb to move anymore. But sort of it's [orgasm] not the same. It's very clitoral now, yeh. I mean I'm retired now so I've tried to experiment in the day when he's [husband] not around and it's been useful because using a vibrator I've been able to, obviously I'm using it as a dilator as well. Ehm but my own sensations I'm tuning in to and seeing the difference. And it's different since I've had the operation." [PT14: 63 year old woman 4 months post surgery / radiotherapy for endometrial cancer]

This woman had begun resumption of sexual activity relatively early in her post-treatment recovery and had decided to use a vibrator instead of the vaginal dilators she had been given to maintain vaginal patency. As a result she had turned what some women
experience as a medical intervention into one that had sensual or sexual exploration qualities for her.

The changes in orgasm mentioned by women did not just emanate from those who had had surgical intervention but were also mentioned by women who had chemo-radiotherapy alone. Delay in orgasm or reduced orgasmic intensity can be associated with changes in vascular and neural function within the pelvis as well as occurring as a result of anxiety, depression and medication used to manage these psychological states. Thus the precise mechanism for orgasmic changes among individuals within this group of women is not clear from the interview data.

Knowledge of such changes is most useful if a comparison can be made with the woman's experience of orgasm prior to illness. For example, one of the women interviewed (PT17) felt that being diabetic had already made her ability to reach orgasm more difficult and so noticed no difference after her chemo-radiotherapy for bladder cancer, and PT18 (46 year old woman, six months post surgery / radiotherapy for endometrial cancer) rarely experienced orgasm when having sex with her husband so did not perceive any difference post-treatment.

However, as sexual assessment is not considered a relevant element of pre-treatment assessment it is not normally possible to compare pre- and post-treatment evaluations of women's sexual health in oncology.

8.6 Coping with sexual pain

In exploring the prevalence of sexual pain experienced after pelvic cancer treatment the women were asked if they had resumed sexual intercourse with their partner following treatment completion and if so had they experienced any sexual difficulties. This meant that women could volunteer whether or not they were currently with a partner, were sexually active in a coital or non-coital sense and what their sexual experiences had been, if any, since they completed their treatment. None of the women interviewed appeared to have experienced dyspareunia prior to their illness. Of the twenty four women who were interviewed for this study, fifteen had attempted to have sexual intercourse with their partner after treatment completion, of which two had ceased sexual intercourse within a short time post-treatment. One woman stopped having intercourse because of her fear of post-coital bleeding and relationship difficulties (PT04) and the other (PT16) because of
severe dyspareunia. Of the thirteen women who were still having sexual intercourse with a partner, four (PT05, 06, 09, 18) had not experienced any sexual pain post-treatment. Six women (PT10, 12, 14, 15, 20, 24) experienced temporary pain in the initial weeks and months following treatment completion but by the time of their interview, from 4 to 24 months later, they were no longer experiencing pain associated with coitus. Three women (PT13, 19, 22) were still experiencing distress associated with persistent dyspareunia at 16, 17 and 31 months post-treatment completion respectively.

Five women who were sexually active prior to their illness had not attempted intercourse since treatment completion between 12 and 29 months previously. Of these five women, two had developed severe vaginal stenosis (PT07, 23) and were unable to use even the smallest of vaginal dilators and the remaining three (PT02, 11, 21) had no sexual desire and expressed fear of resuming sexual intercourse.

Four women did not have partner at the time of their treatment although three of them engaged in masturbation on a regular basis. Two of the single women used vaginal vibrators (PT08, 17) of which one experienced temporary vaginal pain that had resolved by the time of her interview 15 months post-treatment (PT17).

Among the health professionals interviewed for this study, awareness of women’s anxiety about sexual pain was mentioned solely by one of the radiotherapy nurses:

"**Researcher:** Do any of them [women] express any kind of anxieties about being sexually active in the future?

**HCP07:** Yes. Well occasionally, very few patients, but occasionally they'll actually, they'll have that anticipatory worry of, is it going to be painful?"

**[HCP07: Radiotherapy Department Nurse]**

As her comment illustrates, the women themselves rarely voiced such fears or concerns during radiotherapy when their focus was on managing themselves through the acute treatment phase of their illness.

As seen from figure 5.3, discussion of dyspareunia during follow up consultations was raised by health professionals in only four of the seventeen consultations where a sexual issue had been discussed. Sexual pain was not a topic raised by women in observed consultations.
The experience of sexual pain after cancer treatment in this group of women was a relatively common experience which, for the majority, resolved as the women recovered from the acute effects of surgery and pelvic irradiation.

“But we didn't, he wasn't really penetrating me for a little while afterwards because it was hurting as he was trying and he just said 'No, I'm not going to hurt you like this' and so we didn't. So it took many, many months for me to be courageous enough to say 'Just go for it, it's got to hurt for a while.'” [PT19: 62 year old woman 17 months post surgery / radiotherapy for endometrial cancer]

“It was a bit, very, it was quite sore, you know, the first few times. But a lot of that was because I was nervous. And he was nervous that he was going to hurt me, you know. But once we got past that it was fine.” [PT20: 33 year old woman 22 months post chemo-radiotherapy for cervical cancer]

“....Very painful, just especially after the radiotherapy, my vagina was just so sore, everything down there....my bladder, everything. So we made sex other ways, but very seldom.....And I was concerned about whether I did have something [wrong] because the pain just ripped through me, it was terrible. And I wanted to, you know, I wanted to make love and have sex but the pain was putting me off all the time.” [PT24: 54 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

A number of couples had adopted various strategies to try to reduce the pain they experienced during intercourse. One woman spoke about changes to sexual technique that helped to reduce the discomfort associated with deep vaginal penetration since her radical hysterectomy and radiotherapy:

“I find it difficult to be on top now, that is uncomfortable. So we don't tend to do that so much and he likes that, so [laughter] as most men do. So that's one thing that's more or less out the window now. But, you know, the missionary position from behind that, that's OK. I find that, probably because the penetration's not so deep.” [PT14: 63 year old woman 4 months post surgery/radiotherapy for endometrial cancer]

While another found that trying to have sexual intercourse during her treatment period had been too painful but that the discomfort experienced post-treatment completion had gradually eased with the use of extra lubricant and a considerate partner.

“PT15: I think we did it [had intercourse] once while I was having it [radiotherapy] but I did get pretty sore....he's not demanding, he's very gentle and no, I think we got back on track pretty soon. I used the jelly and it was just a wee bit sore. Bit sore, yeh, when he entered.
Researcher: So as a couple how did you manage that, you know, how did you get over that?
PT15: Slapped on a bit more jelly and he was gentle. Once he had entered it wasn't too bad. Yeh, but it gradually got better and I would say it's gone back to normal now. [PT15: 70 year old woman 24 months post surgery / radiotherapy for endometrial cancer]

Although the majority of women who had dyspareunia experienced pain at the point of penile penetration or as a result of friction during thrusting, one woman experienced pain immediately after her orgasm that had not been present prior to her illness. This pelvic pain was still a problem some 12 months post-treatment and she was waiting for referral to one of the clinical nurse specialists for further guidance on this matter.

"Researcher: What aspects of your sexual life have improved [since treatment completion] and what aspects are you still not happy about?
PT24: There are aspects of it have improved immensely. I'm getting very little pain now when I have an orgasm and sometimes I don't get pain at all." [PT24: 54 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

Another woman had vaginal pain associated with her partner's semen, experiencing an unpleasant stinging or burning sensation when he ejaculated into her vagina.

"The main thing that I found that I do find very difficult is once he's ejaculated it stings so much I feel as if I'm red raw inside. It's like loads of tiny little fine needles and it is just awful and I have to go and shower immediately. That helps considerably. But I do think it's getting better. It's not so painful when he does ejaculate; it seems to be a lot better than it was in the very beginning. So whether I am healing there, I don't know." [PT19: 62 year old woman 17 months post surgery / radiotherapy for endometrial cancer]

This woman remarked on how she did not feel she received an understanding response from her treatment team when she brought to their attention the vaginal pain she was experiencing.

"I think I didn't tell him [male doctor] about how much it hurt when he [partner] ejaculated, I don't think I'd got to that stage at the time. And I was saying to him it [intercourse] was very hard, it was very painful and, nice man, I don't mean to criticise.... [Researcher: No, no, say what you feel] Ehm, his attitude was he'd examined me and he said 'Well there's plenty of room in there, I don't see why you are having problems.' And he said that to me on two occasions." [PT19: 62 year old woman 17 months post surgery / radiotherapy for endometrial cancer]
The response of this woman’s doctor highlights the somewhat narrow physical or biomedical view of vaginal capacity taken during vaginal examinations in the medical consultation as opposed to consideration of other reasons why a woman would be experiencing vaginal pain associated with intercourse (Graziottin, 2006).

A smaller number of women experienced persistent pain during attempts at intercourse and depending on the nature of their relationship and support from their partner had either continued with sexual intercourse, albeit at a reduced frequency, had substituted non-coital forms of sexual expression and/or had abstained from any sort of sexual contact because of distress associated with being totally unable to achieve comfortable sexual intercourse.

One woman expressed her sadness that despite having followed all the feminine care advice she had been given by the radiotherapy nurses she still experienced pain associated with intercourse some 16 months after her treatment.

“PT13: Though I used to do what the nurses told me to do but I still, I still experience pain when I’m having sex.
Researcher: In your opinion has your sexual relationship changed because of your radiotherapy treatment?
PT13: Yes. I’ve lost interest in sex. I just don’t feel like it. And sometimes when I do [have sex] I feel some pain. It’s just so uncomfortable.” [PT13: 32 year old woman 16 months post surgery / chemo-radiotherapy for cervical cancer]

This woman continued to have intercourse at a reduced frequency because her partner wanted to be sexual, but she had no interest in sex and experienced pain on each occasion she had intercourse.

Another woman with persistent dyspareunia and considerable sexual fear at 31 months post-treatment spoke of having infrequent intercourse because she felt guilty about depriving her partner of penetrative intercourse which he preferred to non-coital sexual expression.

“PT22: I didn’t think I’d be left feeling like this about sex, the fear of it and how uncomfortable it is. I didn’t expect that…..You know, so now I’ve got a problem and it is very uncomfortable, sore. I don’t really feel I want penetration at all now. I will on occasions to be fair to [husband] and you know, we use a gel or Sylk [personal lubricant]…..
Researcher: Where is the pain, is it around the entrance of your vagina? Is it in the vulva on the outside? Or is it more deep inside?
PT22: It feels to be like that, it’s probably the whole of the vagina actually, as you penetrate in. And I suppose I’m not really relaxing so it’s a catch twenty-two so I
can't really tell. And to be honest we've only actually done it [had intercourse] four or five times since [treatment] really. Not penetrative because I just feel too sore. He finds that a little bit frustrating now but he's good, he's very good about the whole thing. And I suppose for me, sometimes I think ooh, you know, this is not right, but I've got nobody to talk to." [PT22: 51 year old woman 31 months post surgery / radiotherapy for cervical cancer]

As discussed in section 8.1 this woman expressed a number of sexual myths that discouraged her from resuming sexual intercourse. She could not recall being given any information about her sexual recovery, had not been given a set of vaginal dilators to use post-treatment, and had not received any contact details of specialist nursing services available at the cancer centre where she received her radiotherapy treatment.

One couple that had enjoyed a full sexual life before endometrial cancer was diagnosed spoke of their unsuccessful attempts to resume their sexual relationship and the uncertainty about whether or not the pain associated with intercourse would resolve. At two years post-treatment they were resigned to never having penetrative intercourse due to severe radiation changes in the woman's vagina.

"PT16: While I was having the cancer treatment as a result of the surgery therefore that's when I suppose we stopped having intercourse. And then afterwards when we tried it was so incredibly painful that it kept, you know, we did try and then we tried less and less and then I tried the dilator and then it just sort of then fizzled out. Researcher: When you first tried to resume sexual relations how soon after finishing your radiotherapy was that? PT16: It was almost straight away actually. I mean because we immediately went to [country] and then we tried then, yes, so it was a matter of weeks I suppose. Researcher: As you were experiencing that on-going discomfort did you raise that difficulty at all with your treatment team? PT16: No, not then. Later it was, you know, I just thought we had to give it time....Well to be fair [surgeon] actually mentioned it and I said oh yeh [about the pain] and he said we can't have this, can't have this, so that's when he said you must mention it to [clinical oncologist] and he has said that I should, after my May appointment that I should have HRT locally." [PT16: 56 year old woman 24 months post surgery / radiotherapy for endometrial cancer]

"After [wife's name] had recovered from the effects of the operation and the immediate effects of the radiotherapy then we, we tried to restore sexual relations and it, it just didn't work. I mean it was....oh it hurt. [Researcher: It hurt her?] Oh yes. I mean it was impossible and it, despite using whatever one needed in terms of lubricants and so on, it was just impossible. And I think we kind of kept on trying if that's the word, well rather intermittently I suppose, until I suppose almost a year afterwards. When we were on holiday and it, you know it was just so difficult so we said that's it! After that we haven't tried. She went to talk to both the consultant and
the GP and she tried all kinds of things but none of it has an effect because the tissue is so badly, so badly damaged....so it was just impossible.” [PTNR04 51-60 year old husband of PT16]

A number of the women and their partners spoke of their lack of awareness and knowledge about the sexual pain they subsequently experienced post-treatment. This lack of awareness often led the women / couples to naturally assume that they should wait until tissues had healed and that the pain would resolve, rather than ask questions of their treatment team. For the majority this was indeed the case although couples were left unsupported in finding their way through the uncertainty of dyspareunia. Where anxiety, fear or persistent lack of sexual desire had exacerbated the physical experience of sexual pain, these women and their partners had either abstained from sexual contact completely or experienced markedly reduced sexual satisfaction.

8.7 Reduced sexual satisfaction

A number of women in the study felt that changes in their sexual lives following cancer treatment had detracted from their overall sexual enjoyment or satisfaction and that of their partner. The level of distress or concern expressed over changes in the couple’s sexual life appeared to be related to two key contextual factors that have been discussed previously:

- The importance placed upon sexual elements of the couple’s life prior to the woman’s illness.
- The relative importance placed by the woman / couple on a satisfactory sexual life having experienced the threat(s) posed by cancer and its treatment

A 51 year old woman (PT22) treated for cervical cancer 31 months previously expressed sadness that she and her husband could no longer enjoy sexual intercourse because of dyspareunia and her fear that sexual activity could cause her cancer to return.

“Obviously it’s sad, but I am learning to live without [sex] really, you know. Ehm yeh, it is sad really because it would be nice for that to be part of us again, you know, eh.” [PT22]
This woman cried during her interview about the lack of sexual contact with her husband and appeared quite distressed by the changes to their sexual life while other women did not express overt distress and seemed accepting of the changed priority with which they viewed this aspect of their relationship after cancer treatment.

"Researcher: And you said to me in passing when you were talking a minute ago that you don't find sex as satisfying as you used to?  
PT20: No. But I think that's like I said to you, it's [sex], it's, you know, not on the top of my list now so I don't really worry." [PT20: 33 year old woman 22 months post chemo-radiotherapy for cervical cancer]

Reduced sexual satisfaction was also experienced as a result of changes in specific elements of a woman's sexual experience, such as loss of sexual desire or reduced quality of orgasm (section 8.5). Alternatively sexual satisfaction could be adversely affected by reduction in frequency of sexual activity or the associated loss of emotional intimacy due to infrequent sexual contact by the couple.

"And then sometimes I kind of did enjoy it [sex] and it was OK and I did feel a little bit more relaxed afterwards. And actually more it wasn't just about the physical release of sex but the intimacy, the emotional, psychological intimacy part of it that began to feel more important and that I have missed that as well. And it was just a very gradual process and as that started to happen and my libido did start to come back it began to become more enjoyable and more a part of my life again, yeh."  
[PT12: 42 year old woman 14 months post chemo-radiotherapy for cervical cancer]

This interview extract also demonstrates the relationship between sexual satisfaction and other aspects of the woman's sexual response such as her ability to feel desire for sex, the emotional meaning of sexual contact with her partner and the need for gradual reintegration of sex within her life post treatment.

For some women sex failed to give them satisfaction because of the association between sexual intercourse and pain. For PT13, engaging in sexual intercourse had become something she had to endure rather than an activity she enjoyed as she had before her illness.

"But now sometimes it's just like, it's in my mind and I am like 'Can't you just finish [sex] and leave me alone?'"  
[PT13: 32 year old woman 16 months post surgery / chemo-radiotherapy for cervical cancer]
One woman spoke of reduced sexual enjoyment by the couple because their favourite sexual positions were no longer comfortable and so adjustments had to be made to ensure sexual contact didn't cause pain.

"I find it difficult to be on top now that is, that is uncomfortable. So we don't tend to do that so much and he likes that so, eh [laughter], as most men do! Eh, so that's one thing that's more or less out of the window now." [PT14: 63 year old woman 4 months post surgery / radiotherapy for endometrial cancer]

As can be seen from the interview extracts, for the majority of women in the study there had been unwelcome sexual changes that led to reduced sexual enjoyment for the woman and / or her partner. Interestingly one couple experienced improved sexual satisfaction as a result of narrowing of the vagina from surgical effects associated with rectal cancer treatment. As PT09 commented:

"Well I felt physically different, I felt like a virgin. Very, very tight which, you know, heightens the experience really for both of us, so I mean [husband] thought it was marvellous.......I think you know, to begin with I suppose I was concerned about my anatomy, I was concerned about breaking something, you know, tearing something, damaging something, so eh, you know, to begin with I felt like that every single time. And I was thinking, Oh my God, you know, it's awful, well not awful, I was just anxious, and as time went on I became less anxious and, and, no I think the physical experience is, is the same but probably more intense and exciting." [PT09: 50 year old woman 12 months post chemo-radiotherapy/ surgery for rectal cancer]

This extract highlights the importance of exploring sexual changes within the context of the woman / couple's ascribed meaning and unique relationship in order to avoid operating on the basis of assumptions or sexual stereotypes.

8.8 Impact on the Partner

Despite the relative invisibility of the partner or couple within medical consultations witnessed during the participant observation element of this study, the women's interviews speak consistently of the centrality of their relationship and partner to their recovery from cancer. Women spoke about how changes in their sexual identity, function and the relative importance of sex in their lives directly affected their intimate partner.
Many women recalled how initial attempts to have sexual intercourse were naturally somewhat tentative and partners were concerned that they would not cause pain through sexual contact.

"Researcher: What about your husband? If I were to have asked him do you think he felt there was a difference in your sex life after treatment?  
PT15: He probably would. He was more cautious and he was asking me, you know is it all right, I'm not hurting you am I? He was considerate." [PT15: 70 year old woman 24 months post surgery/radiotherapy for endometrial cancer]

"Researcher: Would you say that having had the cancer and the treatment has affected your sexual life in any way?  
PT14: I think it's affected my husband more than me.  
Researcher: In what way?  
PT14: He's got this concern that he's hurting me. And when we first started having sex again he was very hesitant, you know, he'd sort of keep withdrawing himself, physically taking the penis out of the vagina because he was frightened he would hurt me. And when we first had it [intercourse] he was slightly uncomfortable because you could feel because it's obviously got shorter the vagina. And you can feel it hitting up against a brick wall that's there now......but we grinned and bared it, but it was assuring him that it was OK, he wasn't, you know, really doing damage at all. He was concerned that if he penetrated too far then he's rip all the stitches or something." [PT14: 63 year old woman 4 months post surgery/ radiotherapy for endometrial cancer]

One woman who had low sexual desire felt confident that her husband would not expect her to try to have intercourse when she had no personal interest in doing so.

"[Sexual changes] It didn't bother me because number one my husband is very supportive and always he says I will not go for sex unless you have the desire, and I am not an animal. This is what he always says. Always it has to come from both of us and if you don't have the desire I have, I will not do it." [PT18: 46 year old woman 6 months post surgery/radiotherapy for endometrial cancer]

As mentioned previously, this extract appears to suggest that the male partner believes his wife's desire is similar in character to his, despite the increasing evidence that female desire is more likely to be responsive as opposed to the innate drive or desire seen more commonly among men (Basson, 2000).

Another woman felt that it took her partner some time to understand that she had lost all sexual feelings and while he was anxious to resume their sexual relationship, she needed time to regain her sexual identity.
"I think he struggled a bit at first to understand that I just did not have any sexual sensations whatsoever, or desire. I mean we still cuddled and we did have intercourse a couple of times at the beginning of treatment before I started to feel quite sore....I think after I'd finished my treatment he was quite, I guess probably more anxious than me to resume a sexual relationship again and it took me quite a long time....a good three or four months, to start to feel relaxed, to kind of regain my body again in a sense and that part of my identity." [PT12: 42 year old woman 14 months post chemo-radiotherapy for cervical cancer]

As discussed previously in section 8.6, seven women had not been able to resume sexual intercourse as a consequence of their cancer treatment. In couples where sexual intercourse was no longer possible, non-coital forms of sexual expression were often substituted but were rarely seen as an equal alternative to penetrative sex.

"Researcher: So how do you express yourselves sexually together then?  
PT23: Well only, you know, if he masturbates and I'll be with him but he sort of feels rotten about that. I said look, do what the hell you want, you know, for goodness sake, you've got to have some sort of release..." [PT23: 58 year old woman 29 months post chemo-radiotherapy for anal cancer]

"PT22: I actually think in the back of my mind how I got through all this, it's gone, I'm cured, I'm OK. But when you come to the cold, you know, light of day and you're going to bed and what have you it's just like ......and he's very good, he is really, really good, but obviously he has [sexual] needs as well and we just get round it really. Like that for him, you know, manually I would do things.  
Researcher: Right, you mean like masturbation?  
PT22: Yeh, like that. And you know we are very close, we are lucky you know, we are very lucky and care for one another, which is good..... But no, not penetrative because I just feel too [sore]. He finds that a little bit frustrating now, to be honest, but psychologically I think it is the thought now of stimulating anything there. I want to [have intercourse] the need is still there but I'm just scared of what it could bring." [PT22: 51 year old woman 31 months post surgery / radiotherapy for cervical cancer]

Despite the time that had passed since her treatment this woman continued to harbour myths about sex being able to stimulate cancer re-growth and this, coupled with persistent dyspareunia, mean that she and her husband rarely had intercourse.

Among the five couples who were interviewed for this study there appeared to be a close understanding about the feelings each held about the impact of cancer treatment on their sexual relationship. Three of the couples had been unable to resume sexual intercourse
post-treatment due to dyspareunia (PT16 / PTNR04), vaginal stenosis (PT07 / PTNR03) and lack of sexual desire and fear of vaginal bleeding (PT21 / PTNR05).

"Because my husband loves me a lot, I mean he's a really super husband and I think partly he didn't want to hurt me, obviously. And I was worried about it and we talked about it and he said 'No it didn't matter'. He was just pleased that I was here and we have so much because we are a really loving couple, I love him to bits. So it wasn't a problem, it was only a problem that I am thinking for him, but he, I really genuinely believe he doesn't mind. [PT16: 56 year old woman 24 months post surgery / radiotherapy for endometrial cancer]

"I mean from my side it was quite...I guess the most difficult thing for me at the time was, was this sort of, you know, the sort of caveman thing that you can fix everything and throughout all the time we've been married and with the children I've always fixed everything. Ehm suddenly I couldn't. I found that very difficult, I found it very difficult to just deal with that feeling of sort of impotence." [PTNR04: 51-60 year old husband of PT16]

PT07 was a shy woman who became readily embarrassed when talking about sex and tended to offer relatively brief replies to direct questions. She had a close and enjoyable sexual relationship with her husband (PTNR03) who was more open and explicit regarding what the loss of his sexual relationship meant to him. He also talked about how he felt his sexual desire had reduced because it now had no outlet for expression and of the guilt he felt in asking his wife to engage in non-coital sex when he felt there was "nothing in it for her".

"Researcher: Do you think your husband misses being sexual with you?  
PT07: I think so, yes I do." [PT07: 63 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

"As I say, mentally now I think I'm accepting it and I've just said to you there's no change but I suppose in a mental way there's more of a, I can't really explain. I've stopped expecting sex now as such, or intercourse as such. So I have to relieve myself in other ways and as I said to you [wife’s name] does sometimes. I do ask [wife’s name] sometimes [to masturbate me] which I don't like doing because obviously there's nothing in it for her, you know.  
If you said to me today....well it wouldn't be you, if a doctor came in the door and said I've managed to sort [wife’s name]'s vagina out and everything's going to be fine, go home, then I'd probably be like a raging bull if you like. But because that's not going to happen I think mentally I've managed to calm my body down." [PTNR03: >60 year old husband of PT07]

Both PTNR03 and PTNR04 found it very difficult to maintain physical intimacy with their wives while being unable to have intercourse and this was both a personal loss as well as a concern that they may upset their wives.
"Researcher: I guess my next natural question would be if you lose the ability to have intercourse are you still able to be emotionally and physically intimate with one another without intercourse being a part of the picture?
PTNR04: Well we don't, no, well there are two....I think in terms of other sexual activity the answer is no! Because it seems to, it seems to me in any case that to get into a position where if you want to become aroused then it kind of heightens it [the loss of intercourse] and makes it worse.” [PTNR04: 51-60 year old husband of PT16]

"PTNR03: One of the other things is that I don't touch [wife's name] in any way now other than I give her a cuddle round the waist.
Researcher: And why is that?
PTNR03: I don't know if I should try or not, I don't know if she would like me to.
Researcher: Is that because you don't feel comfortable?
PTNR03: No, no, it's not me... I'm thinking of [wife's name] and how she would react to being touched in an intimate way now at this moment. I haven't touched her, I haven't touched her breasts or haven't touched her in any way other than give her a cuddle......and give her a kiss obviously but no, it's a strange thing......I don't know whether perhaps I should make the first move and see what her reaction to that is, maybe?” [PTNR03: >60 year old husband of PT07]

Despite being very close and supportive couples with what appeared to be good communication this extract illustrates the anguish some couples experience in trying to find a way to express themselves sexually within the context of radically changed sexual function and the emotional vulnerability that accompanies the shared experience of a serious illness such as cancer.

Of the two interview couples who had been able to resume a satisfactory sexual relationship that included penetrative intercourse (PT09/PTNR01 and PT10/PTNR02), one male partner had subsequently developed erectile dysfunction (ED) that was being investigated by his GP at the time of his interview for the study. It was unknown as to whether the cause of his ED was related to the stress and impact of his wife's illness on their relationship or an unrelated cause / factor.

"He's been great and I suppose that I can take my lead from him in that he ignored it all [her surgical scars and colostomy], if you see what I mean, for him it's never been an issue......until, ehm, quite recently that he has now got, he is having a real problem keeping, maintaining an erection and this has been happening since Christmas. So he's been to the GP because it's very important to both of us, obviously, and she said it might be a sort of psychosomatic thing from the fact that I've been ill and all the rest of it. Or it could be many other things, anyway he's going for a blood test but he is really having a problem and he's never had a
"So there was a period in our relationship prior to the operation where [wife’s name] felt very uncomfortable and I understood that and didn’t expect there to be any sexual congress. Then post operation, clearly a period exactly the same, then actually things returned to quite normal. [Wife’s name]’s biggest fear was that I would find her unattractive due to the fact that she had a colostomy but that, for me, was irrelevant. But then this [erectile difficulties] occurred just around at the end of the year. I found myself in a position, and continue to do so, whereby, you know, I can get excited, I can penetrate but I can’t maintain. [PTNR01: 41-50 year old husband of PT09]

This gentleman had expressed frustration at not being considered an active part of his wife’s recovery from cancer (section 6.6) and felt that his appropriate support and information needs had not been considered by the medical team providing her care. When he was interviewed it was apparent to me that he felt angry about the suggestion that his ED may have arisen in connection with his wife’s illness and yet no-one from her treatment team had ever enquired about their sexual recovery as a couple.

"The fact of the matter is what has happened [his ED] has happened and the fact that you are doing some research about it is, in my mind, purely coincidental, and I’m not being disrespectful. [Researcher: No, absolutely] The fact of the matter is, you know, I took it in my own hands to do something about it. [seek help regarding his ED]."

[PTNR01: 41-50 year old husband of PT09]

8.9 Category Summary

The data extracts contained in this chapter illustrate the types of sexual difficulty frequently experienced by this group of women and their partners and constitutes elements of core content for a clinical assessment of sexual well-being after pelvic cancer treatment. While fear of resuming intercourse, loss of sexual desire and dyspareunia were experienced by the majority of this group of women, the extent to which these sexual changes were perceived as distressing to the woman and or her partner and the impact on the couple relationship varied greatly. This illustrates the importance of making a baseline assessment of the woman or couple’s sexual and relationship context with which to make post-treatment comparisons in order to determine whether or not intervention is appropriate for the patient.
Women's sexual well-being was affected by a number of interacting psychological, relationship and physical factors that included altered femininity and menopause, relationship difficulties, partner expectations, physical changes in the vagina and altered bladder and bowel dysfunction. Of the four women who did not have a sexual partner at the time of their treatment, three engaged in masturbation on a regular basis illustrating the point that female sexuality could find expression and remain active beyond the context of heterosexual relationships alone.

Only thirteen out of nineteen women who were sexually active with partners prior to treatment remained so post-treatment at the time of their study participation. Three women who had resumed sexual intercourse after treatment continued to experience dyspareunia that caused them distress and relationship tension at 16, 17 and 31 months post-treatment. Five women had not attempted sexual intercourse post-treatment due to severe vaginal stenosis (n = 2) or loss of desire and fear of resuming sex (n = 3). A further two women had attempted sexual intercourse but stopped due to persistent dyspareunia (n = 1) and fear of post-coital bleeding and relationship difficulties (n = 1).

Couples made a number of temporary and more permanent changes to their sexual expectations and expression in order to accommodate the physical and emotional consequences of cancer treatment upon their sexual well-being. This included trying different sexual positions, substitution of non-coital forms of sexual expression and abstaining from sexual contact or expressions of intimacy where that was the best outcome to manage the woman or couple's distress.

The majority of couples continued to hope that the more disruptive changes such as loss of desire, dyspareunia or stenosis were temporary and would revert to "normal" given sufficient time for healing and adjustment to take place. Regrettably as many of the women with persistent sexual difficulties were over 12 months post-treatment the likelihood of spontaneous improvement was unlikely.

In talking about the sexual changes that women and their partners had experienced as a result of cancer treatment it was evident that few had sought or received any direct information about their sexual recovery. Factors that influence the discussion of these women's sexual concerns in the follow-up clinic will be explored in more detail within the next chapter.
Chapter 9: Talking Sex in the Clinic

This chapter explores communication about sexual issues within the context of health care practitioners' professional roles and practice setting as key determinants of effective clinical assessment for treatment induced sexual morbidity. There is an abundance of literature from a range of clinical settings that attest to the difficulties experienced by both patients and health professionals in talking about sexual concerns arising from illness and its treatment (section 2.4). While research evidence about the discussion of sexual issues with people affected by cancer remains limited, clinicians and patients acknowledge that there may be particular challenges associated with talking about sexual concerns within the context of cancer treatment. The discussion of sensitive quality of life issues such as sexuality with people affected by cancer remains a challenge for practitioners despite improvements in survival rates. This is because cancer continues to threaten the survival of many individuals and as a disease has retained its capacity to generate fear at an individual and societal level.

This data category explores the specific factors that influence communication about treatment related sexual concerns between patients and their partners and health care professionals.

9.1 Barriers to the discussion of treatment related sexual difficulties with women

Factors identified as likely to reduce the likelihood that treatment related sexual concerns would be discussed within the follow up clinic were readily elicited during interviews and analysis suggests they emanate from:

- The clinic environment
- Oncology follow-up processes
- Health professional characteristics
- Patient characteristics
- Characteristics of cancer as a serious and potentially life threatening illness

The relative importance attributed to specific communication barriers identified by health professionals, patients and partners is summarised in figures 9.1 to 9.3.
9.1.1 Factors within the clinic environment and the processes of medical follow up

Elements of the clinic environment and its processes that were mentioned by health care professionals and patients or partners as having had an adverse effect on the discussion of treatment related sexual morbidity within consultations are summarised in figure 9.1.

Figure 9.1: Comparative frequency (%) of organisational factors identified by health care professionals or patients / partners as barriers to communication about sexual difficulties in the clinic

These factors included lack of privacy, the presence of additional personnel within the consulting room, and time constraints inherent to what was often considered heavy clinic workloads for practitioners to manage. Although a lack of privacy in the clinic or hospital environment is cited in published literature as a barrier or constraint to the discussion of sexual issues within the clinical setting (Wilson & Williams, 1988; Lawler, 1991; Guthrie, 1999; Sardaki & Rosenqvist, 2001), a lack of environmental privacy was not a common reason cited by either health care professionals (n=2) or patients (n=1) taking part in this study.

However, a feature of the consultation process mentioned by both patients and health professionals that adversely affected privacy in the clinic, and inhibited the discussion of sexual concerns, was the presence of either the patient's partner or additional health care...
personnel within the consulting room. Patients appeared to be less concerned about the presence of other health professionals (n=3) or their partner being present (n=2) than health professionals were. Health professionals frequently cited (n = 9) the presence of the woman's partner as contributing to communication difficulties or generating embarrassment for them or for women when sexual issues were to be discussed.

"Researcher: How does that leave you feeling when there's another person in the room?\nHCP01: Yes...I'm probably more conscious of the fact that it's a difficult question [about sexual issues] when someone else is there. Ehm, sometimes you find the husband will answer for the woman and say 'Oh, you know, it's [sex] difficult' or vice versa I've had that with men and the woman telling me well sometimes it works [Laughs] and sometimes it doesn't, for impotence. Ehm, so, yeh I think I prefer if it's just the woman on her own, definitely, it's easier. 'Cos then you're only dealing with one person's embarrassment [Laughs] ...or two...yours and theirs! [Laughs]"

[HCP01: Female specialist registrar]

"Well I sometimes think that it's inhibiting in that I don't think the patient always wants to talk in front of their husband or partner, ehm, and I think too that women will tend not, if there's the male partner there they won't talk about their needs, they'll be thinking about what it's going to, what impact it's [talking about sexual concerns] going to have on him, how embarrassed he is going to be, how humiliated he's going to be, rather than sort of opening up about it themselves, it will all be modified by the third person there, yeh!"

[HCP08: Female consultant clinical oncologist]

Health professionals also felt that the presence of additional colleagues in the consulting room (n=10) inhibited them from asking questions about a woman's sexual recovery. Some health professionals felt that the presence of additional personnel caused embarrassment for the woman, which prevented her from answering questions freely; others appeared to be more concerned about personal embarrassment emanating from being observed by colleagues talking about what was considered a sensitive and private topic that was already challenging to discuss in the clinic setting.

"....the other thing was that I took her [female patient] out of the clinic setting because there's about six people in there and it's like an entourage and he [consultant] didn't like that very much, but I said to him... he said 'Oh, is she very shy?' I said well, to be easy, I just said 'Yes!' Because if I just said 'No' it would have been more of a problem for me to have got her to be seen by just me and him."  

[HCP04: Female clinical nurse specialist in gynae-oncology]

"Sometimes that, that can just be a little bit, just creates an environment in which you aren't comfortable assessing such things [sexual issues]. For example
sometimes you'd have a medical student or, you know, a visiting fellow as we have at the moment and a nurse in the room. Very hard to discuss proper issues [sex] then. I mean perhaps I should turf them out, and you do from time to time, but it just makes it more awkward.”

[HCP03: Male clinical research fellow]

A factor that health professionals (n=11), patients and their partners (n=8) agreed prevented them from discussing sexual issues was the time constraint inherent to busy follow up clinics.

"I'm very conscious of how late I'm running, yeh, I don't like being late....And also it [sex] takes a long time to talk about if there is a problem so yeh, you might skip it if you were in a real rush.”

[HCP01: Female specialist registrar]

Some of the women interviewed spoke of feeling rushed by health care personnel so that they did not feel in control of what was happening to them and felt unable to raise anything other than the most immediate or pressing issues with their treatment team.

"....Because even when you go for the check up it's still very much about the clinical side of it, you know, the internal examination, how you're healing and all that stuff. I mean I felt able to bring up the HRT thing but I kind of felt, it all feels a bit rushed when you go in....you kind of feel when you are in the hospital everything feels kind of quite pressurised, like you need to kind of like in and out, like when you go to the GP.”

[PT12: 42 year old woman 14 months post chemo-radiotherapy for cervical cancer]

"Researcher: Would you feel able to ask your medical treatment team, you know, during the follow up period you are in now?
PT14: They're never as relaxed as we two are now and there's always the pressure of time when you go in to see the doctors. And half the time, you know, they're, I'm sure they are trying to get rid of you before you even get in there [Laughter]. You know, and the nurse takes you into a room and the doctor appears and 'go up there' and you know, 'take your clothes off', and they examine you and, and they've gone and nurse is in and, you know, it's like you're on a treadmill, you know, and to be able to sit down, like this, that's not possible and that's a shame.”

[PT14: 63 year old woman 4 months post surgery / radiotherapy for endometrial cancer]

Other women spoke of feeling that they were "taking liberties" with their medical team if they had too many questions to ask within what they perceived to be a busy clinic.

" No...I, I...I do [ask questions]. I mean I used to carry a hideous notebook which used to frighten everyone from the questions [both laughing] Yes it's like oh god! So I will, but...but on the whole when I come and see him I always get the impression he's pretty damn busy and ehm.....(pause) so you know, I mean, like I said, you know when I, if there are questions that need to be asked, I'd ask.”

[PT01: 45 year old woman 21 months post chemo-radiotherapy for cervical cancer]
"I was going to actually ask the doctor next time I come about my sexual activity, because as I say I had so much going on because I have had a lot this week. And I keep getting all these pains and then they said to me that I need to go and see gastric. But then it went, the pain went for a few weeks and of course I said to him [doctor] 'I don't need to see it [gastroenterologist] now' but of course the pain is back again so by the time you've got all that out I don't like to say 'Oh, and by the way, so and so' because he might think 'Bloody hell!' I think he thinks you are taking liberties because you are asking all these questions, because you have got these problems and then you put another problem on top [laughs] I don't like to ask!"

[PT02: 51 year old woman 12 months post chemo-radiotherapy for anal cancer]

It was interesting to note that none of the private patients interviewed [n = 6] cited time pressures as an inhibitory factor influencing their consultation. One of the consultants interviewed specifically commented on the contrast between her private and NHS follow up clinics regarding the factors that influenced her ability to address the sexual concerns of her patients.

"I think it's very different with my NHS practice from my private practice. And I think it's two factors: in the private practice patients are often in socio-economic group one, they're very much more attuned to discussing psychological problems, there is more time in the private clinic and I see the patient every time. I think to discuss sexual problems in an NHS clinic is often difficult for the patient. I think it's difficult if they're seeing a different registrar each time they come. They perhaps find it easier if they're seeing me because they have the reference point but there's always the problem of time in an NHS clinic."

[HCP20: Female consultant clinical oncologist]

Five health care professionals considered the discussion of sexual concerns to be more time consuming than other topics because of its sensitive nature and the time needed to establish both a rapport with the patient and to determine the personal context for subsequent patient information, referral or clinical intervention.

"Psychosexual issues you know, issues about body image and all that, and I think you can't cover it in five minutes and that's one of the reasons why we sometimes don't address it because we know we've only got five minutes, if we go down this route now then you know all these other problems, ehm, you know we will run into problems and there are so many patients waiting."

[HCP13: Female specialist registrar]
“But when it comes to talking about, you know, personal problems or you know it's something that can be highly emotional to a, to a particular person, er when it comes to say things to do with their sex life or any sexual dysfunction or any particular problem, ehm, you will actually find yourself not getting to the point straight away because you have to find a way to get to that point by just talking about other things first and then moving on depending on what your rapport is and, you know, that's going to take you ten or fifteen minutes, you know, that puts sort of a little bit of pressure, so…”

[HCP14: Male specialist registrar]

An interesting difference between health professional and patient opinion was in relation to the importance participants placed on the continuity of health care personnel during women's follow up clinic attendances. A number of patients and partners (n=8) mentioned the negative impact of having to discuss such a sensitive aspect of their life with a series of different doctors due to junior medical staff rotation and a follow up system which did not appear to prioritise continuity of personnel. None of the health professionals specifically identified discontinuity of personnel as an inhibitory factor in discussing sexual morbidity with patients.

“I thought ‘Oh no, I’ve got to go over it again now.’ He [new male doctor] wasn’t sure of something and then I heard him say oh no, that’s normal, that’s to do with the scar tissue or something. And I had to have my bowel examined again, But I was going to tell the other one [previous doctor she had seen] but I thought ‘No’ keep your mouth shut, I’ll tell the nurse….But I know they've all got to learn but it is hard when you've got to have a new one, you know.”

[PT04: 64 year old woman 8 months post chemo-radiotherapy for cervical cancer]

“I would think that's probably the right place [follow up clinic] because I think if you start introducing too many people it becomes more and more remote. As I say you've probably got [consultant's name] there but you see her once in a blue moon, in the nicest possible way. And you don't, there isn't the continuity and that isn't a criticism, it's just a fact.”

[PTNR02: > 60 year old husband of PT10: 68 year old woman 24 months post radiotherapy / surgery for rectal cancer]

A number of health professionals (n = 8) felt that sexual morbidity was not given the same profile in terms of documentation or service provision as other treatment related toxicities and late effects. This lower profile, together with an awareness of clinical time pressures, meant that health professionals were unlikely to prioritise the discussion of sexual morbidity at key points in the patient’s treatment journey over the discussion of, for example, fertility, menopause or bowel and bladder toxicity.
“Yeh, and maybe make more of a point of it in the consent forms because I think in the consent forms they talk about fertility and menopause but they don’t talk about vaginal narrowing so I think that probably does need to be addressed as a common side effect, so it should be on the list shouldn’t it? It’s not there, yeh, so I think it’s just got forgotten probably.”

[HCP01: Female specialist registrar]

“You see patients, if they want to talk about it, I suppose my concern is that we don’t have a blanket question that you ask everybody when they come back [for follow up]. You see I... there is much less written about this [sexual issues] than there is written about bowel and bladder toxicity. But if you open and you dig a little bit more and actually this is what I do, because I know, because there’s a lot more written about it and you know that it’s [sexual issues] very poorly documented.”

[HCP05: Male specialist registrar]

“Researcher: Why do you think that even doctors who are very comfortable in the private elements of people’s bodily function, that sex is somehow treated differently?

HCP08: Well firstly I’d absolutely agree with you that it [sex] is treated differently. And yeh, I don’t know at all why but yes I think you’re right, one feels very comfortable asking about the most horrible questions about bowel and bladder. But it’s kind of, there’s a sort of barrier, there’s something about Just getting into sort of sexual function in the same way. Maybe it’s because it involves a third party?”

[HCP08: Female consultant in clinical oncology]

This reticence to discuss sexual morbidity was reinforced for many by a lack of awareness among health professionals regarding the provision of services for the management of female sexual difficulties. Health professionals interviewed were unaware of referral pathways within or beyond the cancer centre where women with identified sexual difficulties could be managed.

“I’d phone them [Gynae-oncology CNS] up and go, I’ve got this problem and who, what’s the best way to go about it because they probably know best the services to access because I’m not really aware about services at this hospital and also because patients come from far and wide.....so I tend to be guided by them and if they weren’t there I’d be quite stuck.”

[HCP06: Female specialist registrar]

“I suppose it’s again just a sort of general awareness isn’t it? I mean there’s much more in the literature about male sexual dysfunction after these treatments, after prostatectomy, and there’s so very little....and then it becomes quite difficult to discuss issues about [female sexual problems] when there’s very little information and I think it just really comes from, from that. It’s the uncertainties and the lack, of our own inadequacies, really about, you know, knowing what to do with the situation maybe.”

[HCP08: Female consultant in clinical oncology]
A number of health professionals (n = 5) felt that it would be inappropriate to enquire about sexual difficulties without being able to offer women either an intervention for their sexual problem or referral to a suitable specialist service.

"...And it's partly the personal impotence of not knowing what to do if we come out with it [asking about sexual concerns] apart from extending the session and counselling them more and just sort of talking them through it and knowing that they might feel better for the hearing. Ehm, but it does feel a very unskilled, untrained raw, you know, unprofessional area in a way. Not....don't really feel sort of equipped to take it to any sort of level.
You know I think in most places, again because we've got systems, we know we've got steps we can take which makes it terribly much more, ehm, appropriate somehow to kind of open the door, if you open the door you want to know you're going somewhere. Don't you?" [HCP08: Female consultant in clinical oncology]

Patients did not specifically comment on a lack of services regarding sexual morbidity although some did refer to being aware of the higher profile given to some treatment toxicities, such as bowel and bladder toxicity, than that given to sexual morbidity. This disparity was also evident in the participant observation findings discussed in section 5.1.

"You know, because there's a huge amount to take on board at the beginning.....But they seem not to worry about giving you a massive amount on the bowel and the bladder. Why does everybody pussyfoot around the other [sexual] bit?" [PT03: 55 year old woman 8 months post surgery / radiotherapy for endometrial cancer]

A consistent comment made by women in this study was that they had not been given information about who was the most appropriate person to contact should they have any treatment related sexual concerns. This lack of information served to further enforce the invisibility or illegitimacy of sexual morbidity as an aspect of pelvic radiotherapy late effects management in medical follow up.

"I think if I had problems I would have waited until I had, it was a really big problem. Before then I'd try and research then, who am I supposed to phone to find out about [sexual] problems? And because it's a sexual problem you don't just want to phone up say your consultant, or your, you know, who do you speak to, you know?"
[PT05: 36 year old woman 12 months post surgery / chemo-radiotherapy for cervical cancer]
"I coped with most things very well, even though I was on anti-depressants, but I can remember it [sexual concerns] occupying quite a bit of thought and my time and I didn’t have anybody to ask….I just didn’t know who to ask.”

[PT24: 54 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

9.1.2 Health Professional Characteristics

Interviews with both health professionals and patients identified a number of perceptions related to health professional role expectations, practitioner’s communication style and perceived expertise that decreased the likelihood that discussion about women’s sexual concerns would take place between health professionals and patients or their partners.

Figure 9.2: Comparative frequency (%) of practitioner characteristics identified by health care professionals or patients / partners as barriers to communication about sexual difficulties in the clinic

As highlighted within published literature (chapter 2.4) the discussion of sexual issues within opposite gender consultations was often considered more challenging than those
where the patient and practitioner were of the same gender. Although seven health professionals (three male doctors, one female doctor, two female nurses, and one female radiographer) stated that they felt women were more likely to prefer to speak to a female clinician regarding sexual concerns, only three patients specifically stated that this was the case.

"Researcher: Do you think as a woman you’re more inclined to ask questions about sexual issues than some of your male colleagues?"

HCP01: Hmmm....I’m sure it’s easier, like I hate asking about impotence. Yeh I really hate asking about impotence but probably it’s easier for a man to ask and probably easier for the male patients to talk to a male doctor, ’cos they see a young girl come in and they think ‘Oh my God, I’m not going to mention THAT, I think definitely!’”

[HCP01: Female specialist registrar]

"Researcher: The fact that you are a male doctor and that this is a group of female patients, does that alter the way you communicate about sexual issues do you think?

HCP14: Ehmm I think it does to an extent because, ehmm, as you know, as you are of a different sex you can’t understand every, you know, what their major priorities are going to be. And the only way you can understand that is actually, ehmm, you need to think about your own, you know, if you have a female partner, you think about your female partner’s you know, priorities, needs and wants and, you know, and then you I think personally you’d find that you don’t actually want to think about that in relation to this patient, sort of thing, because it’s just not right! So therefore I think it does sort of make it a little bit more difficult. If, you know, you’re talking to a male patient there’s already a good level of mutual understanding and you can sort of get away with terms, well you know what I mean by that when I say this and…and you know that they will actually understand that so to broach it with a female patient does sort of make that line of communication a little bit difficult.”

[HCP14: Male specialist registrar]

One patient’s (PT24) preference for a female doctor was based on her strict catholic upbringing and this had prevented her from raising sexual concerns during routine follow up visits when she more commonly saw a male clinician. She had also given false information to male clinicians completing clinical trial toxicity documentation stating she had no sexual difficulties because she did not want to elaborate on her problems with a male doctor.

"Researcher: At what point did you raise your sexual concerns with your treatment team back at the [cancer centre]?

PT24: Ehmm, only, only when I had a woman doctor.......And so, but I only spoke to her and I can remember maybe a couple of male doctors.......and they asked me how was my sex life and I can remember telling them and saying ‘It’s fine thank you’. Telling a lie straight out but I just felt I couldn’t tell a male doctor.....Yeh.
think it's just my upbringing, catholic upbringing and whatever. And I was really hoping I was going to get a female doctor, yeh, I think she did ask me a question, like they always did ask the question, because I said I told lies before. And it would depend how many people were in the room. I was brought up, I had six brothers and then there’s three girls and Mum always taught us girls to be very discreet....And those sort of things were not discussed about in front of your brothers that that's, maybe I'm prudish but I can't talk to a male about it other than my husband.”

[PT24: 54 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

This particular finding, albeit from only one participant, does raise interesting questions about the assumed reliability of clinical research data on sexual morbidity which may be more open to inaccuracy because of difficulties in disclosing what many people perceive to be sensitive personal information.

The majority of women, however, did not find a male clinician a barrier to discussing sexual concerns, stating that the relationship and rapport they had with their doctor was more important in creating comfort and confidence in communication. Data examples of factors that enable the discussion of sexual concerns are discussed in section 9.2 and summarised in figure 9.4.

Communication difficulties between health professionals and women were cited by both groups of participants as a common reason for avoiding the discussion of sexual concerns. Perhaps unsurprisingly, thirteen health professionals gave examples where women had closed down communication opportunities or whose demeanour was perceived to be awkward or embarrassed and that this had inhibited the practitioner’s ability to discuss sexual issues within the consultation.

“I think you are led by the patients so much. Ehm it is very difficult, it is an area that we are uncomfortable talking about, we shouldn’t be but we are. It’s, it’s quite obvious from a patient’s body language they might not be happy to discuss this. Or they close the subject really quickly and say ‘Oh well, we’re not having sex anymore.”

[HCP12: Female clinical nurse specialist in GI cancer]

“Because they [patients], they don't want it, they just block off and you know, you just mention something else, but close to sexual function it’s just like a wall, you can’t talk to them, so I might never talk to them...”

[HCP14: Male specialist registrar]

“....And when you’ve found the patient saying well, you know, giving you rather negative feedback about the fact that they’ll never return to sexual intercourse again, those people tend to, I find they tend to stick with me and I find it difficult to know how to deal with that issue subsequently. And there was one example of a
lady who physically did recoil when I talked to her about the potential side effects of radiotherapy and the fact that she would have to use dilators. She found that quite distasteful and she was quite a young lady, she was I think in her fifties. And she certainly gave us lots of problems post-treatment in terms of trying to talk to her about sexual issues after treatment.” [HCP19: Female consultant clinical oncologist]

No health professional explicitly stated that they felt their personal communication style or approach would inherently prevent the communication of sensitive information such as sexual morbidity. Yet in contrast, eleven women felt that either poor timing of information about sexual issues or an awkward or unhelpful communication from health professionals had or would inhibit them from approaching specific health professionals about sexual worries they may have had. One woman, a practising health visitor, told of her discomfort when intimate information about vaginal dilation was delivered to a group of four women in the radiotherapy department, all with very different personal and disease related circumstances.

“When I went for the internal radiotherapy when we had the little group discussion with three ladies and myself.....with a lovely nurse who came with little packs of dilators and everything and talked about being sexually active and I think that was the first time anybody had sort of talked about it, and the lady who didn’t talk much said ‘sexually active would be a fine thing if I only had a man.’ And the lady who’s prognosis wasn’t terribly good said ‘that’s the last thing on my mind’ And I think I just sat there and nodded because these were two very sad people and I got the support of [husband] and everything and didn’t want to shout, ‘oh I’ve got a lovely husband’ when people have got horrid things going on. So she gave us the dilators and told us if we were currently sexually active, bearing in mind this is still only about six weeks post-op, that we didn’t need to worry about it, but if we weren’t then to use the jelly [lubricant] and the thing [dilator].”

[PT11: 59 year old woman 12 months post surgery / chemo-radiotherapy for cervical cancer]

Seven women and one male partner gave specific examples where they felt they had been put off talking about sexual issues to other personnel by the negative response or attitude of a practitioner they had encountered during their follow up at the cancer centre.

“....she [radiotherapy department nurse]gave me the impression, now this is probably not the truth, but she gave the impression, and that’s what matters, of being bored and disinterested and I realised that maybe it’s the sixth thousand four hundred and thirty-fifth time she’s taken somebody through pelvic radiotherapy and talked about dilators . But honestly, for the patient it’s the first time. And she just gave me this thing and asked me to read it through, the horrible little leaflet where it talks about it here, internal radiotherapy, radiotherapy, about douching and then
about using the vaginal dilator.....she sort of talked about the vaginal dilator and she sort of gaily said things like 'Well you'll have to use that for the rest of your life' which is a pretty daunting prospect and, you know, pretty horrible and pretty scary frightening and you know, just the way, she was so brusque and so kind of, she was almost unkind about it. I just sat there and I'm afraid I burst into tears, it was just before I started radiotherapy...." [PT03: 55 year old woman 8 months post surgery / radiotherapy for endometrial cancer]

"Researcher: And have you asked them [treatment team] about sexual changes?
PT19: The only person I have mentioned it to is [HCP02: consultant] and said to him that I was having problems and at that time I was saying, I think I didn't tell him about how much it hurt when he [partner] ejaculated, I don't think I'd got to that stage at that time. Ehm, and I was saying to him it [intercourse] was very hard, it was very painful and nice man, I don't mean to criticise, his attitude was he'd examined me and he said 'Well there's plenty of room in there, I don't see why you are having problems.' And he said that to me on two occasions. And I thought well there's no point in pursuing this really. Not that I particularly wanted to pursue it with him, but I just expected, oh not say expected but almost wondered if I'd sort of get some sort of a more positive reaction about well, you know, you could be doing this or you could be doing that. He might have said to me 'Were you given dilators?' and I probably said yes, but I can't use them. Whether he felt well, you know, we've given you some help and you're not helping yourself, I don't know. But no, I didn't get an awful lot of good response from that." [PT19: 62 year old woman, 17 months post surgery / radiotherapy for endometrial cancer]

A number of health professionals (n = 9) acknowledged that they found talking with patients about sexual issues inherently embarrassing, with some giving examples of situations they found particularly challenging such as talking to patients when their partner was present, talking to patients in same sex relationships or simply worrying that they might elicit information about individual sexual practices that might cause them disquiet.

"I suppose if I do have a problem it's if, personally, it's if he brings something up, so if the partner just out of the blue brings up something about her [patient], that throws me, that would be the only time I would probably blush."

[HCP09: Female clinical nurse specialist in gynae-oncology]

"I haven't talked to anybody with same sex partnerships ever, I think [gynae-oncology CNS name] has talked to some there. But I don't know how I'd tackle that. I would find that quite a difficult area, not having had any specialist training."

[HCP16: Female therapy radiographer]

"And that was only once I was embarrassed and she had a patient and I was there and the woman was talking like her husband couldn't have an erection and he was putting a bottle inside her and I was so embarrassed.....I was so shocked because I never heard that before. But I just couldn't understand people do such things, you
know, it was so strange to me, never heard about it before. So I was embarrassed then, that was the only time.”

[HCP15: Female outpatient staff nurse]

Two women expressed concerns that the health professional to whom they had been talking had been embarrassed by the mention of sexual concerns. PT 04 perceived a young male doctor she saw would be embarrassed by the questions she wanted to ask about her sexual recovery and preferred to talk to the consultant's medical secretary as they had a nursing background and a good rapport with patients.

“You know, the young one that's there now, the man, ehm I don't think that I would, some people would ask him. And I might not even ask him because I think to myself no, it wouldn't be fair to him, he's young, he might go all red or something.

Researcher: You think he might be embarrassed?

PT04: Yes, I wouldn't care what I said, but it was the way he would take it. I probably think to myself, no, I wouldn't. I would be on the phone to [consultant's secretary] but not everybody can talk to a man like that.”

[PT04: 64 year old woman 8 months post chemo-radiotherapy for cervical cancer]

Whereas PT14 had experienced awkward verbal and non-verbal communication from a female nurse in the radiotherapy department that led her to believe that the nurse was not comfortable answering questions she posed regarding her sexual recovery after treatment for endometrial cancer.

“PT14: I found with her there wasn't a lot of eye contact, she would sit, you know, at her desk with it [feminine care leaflet] 'And you read this and I'll do that' and it wasn't like we are talking now. And sometimes she used the expression 'down below', which I was quite surprised for a nurse to use, especially in this day and age, when everybody seems to be at it [sex] every five minutes of the day, you know. And I thought that's a bit odd.

Researcher: So what did you make of that, what did you put that down to?

PT14: I don't know if it was embarrassment on her part, because obviously I spoke to her about sexual things. You know, it was sort of, it was her way of coping with that by not sort of having eye contact. That she was very much on the medical side and, you know, she says 'Oh you can have sex, that's alright, enjoy it.' But there was still no eye contact with her, she was still at her desk, you know, sort of thing, and 'Don't forget to use, you know, to do the douching, you are doing the douching?' every time she saw me. So it was very much on the physical side, you know, the medical side I would say.”

[PT14: 63 year old woman 4 months post surgery / radiotherapy for endometrial cancer]
Although such an experience meant that this confident woman would not approach this particular member of staff, she had not been dissuaded from pursuing information she sought from other sources such as the internet.

Two male partners also felt that certain health professionals found talking about sexual matters embarrassing, particularly when they accompanied their wives in consultations.

“Yeh, I wasn't embarrassed when she [radiotherapy department nurse] was talking to [PT07: wife]. I didn't sort of join in but she was, but I just felt she was very pleasant, but she made a couple of sort of jokes about me being there, as if it was the first time she'd ever had a man in the room with her when she was talking to a patient about these things [dilators], you know. So I didn't go with [PT07: wife], she saw her about three or four times I suppose but I didn't, I only saw her the once.”

[PTNR03: >60 year old husband of PT07: 63 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

Health care professionals acknowledged that they often felt they did not have the expertise (n=11) to offer detailed explanations about sexual dysfunction to patients or, more commonly, to offer a specific clinical intervention to resolve a woman's sexual difficulty. Concern about lack of expertise affected all professional groups (doctors, nurses and therapy radiographers) but for some doctors this lack of knowledge appeared to be related to what they saw as their dominant role in managing the physical or biomedical aspects of the woman’s cancer treatment as opposed to psychological or social aspects of care in which they held less interest and felt they had less expertise.

“I think in some ways in a busy clinic that's important because it's got to be about the disease. And very often, in terms of psychosocial issues, in terms of chronic side effects there should be, I would feel there should be more of an emphasis upon late side effects, sexual and whatever others. In terms of psychosocial issues often the doctor is a poor person, or the worst person you could talk to about. Because certainly there isn't an appreciation of issues like that and apart from referral on to someone else, which I suppose is an important axis of referral, but really, it's often a poor person to talk to anyway about such issues. Do you know what I mean?”

[HCP03: Male clinical research fellow]

“And it will take time because what you do open up when you start addressing it [sexual concerns] and I think, I think at the bottom of all this is we don't have the help to offer them, we don't have the skills I don't think, enough of a skill, we've got some people with good communication skills in just supporting them, because people don't want an answer now, they just want somebody to talk to initially. You know, there is help, this is quite normal, you know....and some of them are very deep rooted problems the cancer opens up. You know, there may have been problems
before and if you can pick that up and just re-refer them it's just that then they've got someone. I don't think we'll ever have all the skills to deal with somebody's problem but I am sure it's because time and lack of skills.....And we have such a medical model approach to patient care.”

[HCP10: Female clinical nurse specialist in colorectal cancer]

Three women and one partner felt that specific practitioners they had encountered did not have the expertise to assist them with the sexual difficulties they had encountered post-treatment and a number of women (n = 6) felt there was uncertainty as to the most appropriate member of the health care team to approach regarding sexual concerns, as none of them had been given specific contact details of a team member to whom they could address such questions.

“Somebody who specialises in that side of it [sexual concerns] that you, you wouldn’t feel as though...because even now I don’t really feel I could actually go in to my specialist and say that, because it’s not his forte , it’s not his field is it, really? He’s concerned in keeping me alive and what’s the best thing for me.”

[PT22: 51 year old woman 31 months post surgery / radiotherapy for cervical cancer]

“...the stoma nurse, very embarrassingly, said to her [PT07] she said I want to talk to you two about your sex life. So I thought right, ok, so that won’t take long, and she just laughed and she just come out with [PT07] and she said 'Right, now, your sex life.' So I said well we haven't got one at the moment and she said well, it was funny really because she said 'Well, what I suggest is you try different positions.' And I said, well OK and that was it, that's, I think honestly that is the only mention of our sex life that has ever been mentioned......I don't know why, as I say, I just felt someone had just said to her 'You'd better talk to these two about their sex life' and she thought 'Blimey! How did I get landed with this job?' [laughter] She obviously, I mean obviously she's not trained in that field because she had to sort of, well I say, no skills. But it was just strange, it was a strange thing, you know, a strange person to and that was it, that was all our dealings about our sex life.”

[PTNR03: > 60 year old husband of PT07: 63 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

As mentioned previously, a number of both health professionals and patients questioned by whom the assessment and management of treatment induced sexual difficulties should be undertaken. Five of the eleven doctors interviewed felt that patients did not expect them to address sexual morbidity within their role. The reasons given for these views included medical paternalism, the hierarchical nature of doctor/patient relationships and the fact that patients would not expect their oncology specialist to ask them questions about their sex life when they attended for cancer follow up.
"...generally in society it's [sex] not something you talk about really, it's not something you talk about in a cancer clinic and, you know, as I said, sometimes it's the last thing on a patient's mind."

[HCP14: Male specialist registrar]

"Researcher: Do you find women spontaneously asking questions about sexual worries or concerns?

HCP18: Er, again, infrequently......I think the doctor-patient relationship's an interesting one, it's fairly paternalistic, autocratic set up and the UK's about as bad as anywhere."

[HCP18: Female consultant clinical oncologist]

"I've yet to have many people who actually volunteer to me, I mean they probably tell the gynae CNS, but I've had very few people that have come to me and said 'Look, you know, I have difficulty with sexual intercourse, what shall I do doctor?' And I don't know whether or not that's because we have such excellent gynae-oncology CNS that they pick them up and deal with it, or whether it's the fact that patients possibly don't necessarily think that it's an issue they can raise with us as their oncologists. I don't know.....and maybe it does reflect some level of discomfort in talking about sexual issues that we actually produce, I suppose."

[HCP19: Female consultant clinical oncologist]

One partner spoke particularly about accompanying his wife to medical consultations because of her reticence to ask questions of her doctor as she felt inhibited by the hierarchical nature of their relationship.

"But [wife's name:PT07] was there, but terrible, she won't ask doctors anything. She still has this attitude doctor is god and that's why she, I don't suppose you remember she made a remark to you when I was here last time, she said, 'Oh he talks too much' But that's why I love, that's why I always make sure I'm with her on all these interviews and consultations, I'm always...because I ask questions."

[PTNR03: >60 year old husband of PT07: 63 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

These expressed beliefs from doctors were endorsed by eleven women who gave a variety of reasons why they did not expect this aspect of care to be provided by their oncology specialist. Three women believed that their medical team were solely responsible for effective treatment or cure of their cancer, while eight women felt that addressing sexual morbidity was not a doctor's role. Some women felt they may be considered a "nuisance" if they took a sexual concern to their consultant, medical team or even their GP.

"I mean because you do have your own doctor and I don't, well I presume, you see its [sexual concerns] almost not exactly a problem is it? Not a medical problem....But there isn't a cure of any particular sort is there? I am sure there are ways of making it [sex] easier but it's not actually, I don't feel it's something you will
go to your doctor about, you know. Ehm and I'm not sure you would approach the team here, you do tend to think of them as the cancer only team, you know."

[PT17: 67 year old woman 15 months post chemo-radiotherapy for bladder cancer]

"You definitely, most certainly need somebody that would follow through from your specialist I feel because one, it's unfair on your specialist to have to get bogged down in these issues, they are not life threatening and they're caught up in your survival, you can survive without that [sex]. And I just think going forward if anything could come from this [taking part in the study] it would be nice for anybody in my position now that they could latch on to somebody that wasn't just caught up in, you know, the survival thing side of it."

[PT22: 51 year old woman 31 months post surgery / radiotherapy for cervical cancer]

"Researcher: And how did you find that when you actually raised it, how were your questions responded to? 
PT23: Well I think they found it a little bit of a nuisance, you know, why is she going on about the dilator? And I thought well, you know, hell it's supposed to be getting better and it's not getting better. So I did push quite hard, you know, I'd mentioned, I mean obviously it was 'Oh well I suppose we've got to deal with this sort of thing', you know. That's the feeling I got, I was being a nuisance, But I thought, you know, I want to know and if you can't tell me, who can? So I mean I am a bit persistent.”

[PT23: 58 year old woman 29 months post chemo-radiotherapy for anal cancer]

Perhaps linked to the belief that addressing sexual morbidity was not a dominant aspect of the specialist medical role there was broad agreement between the women (n = 13) and health professionals (n = 12) that sexual morbidity was given a relatively low priority by health professionals when compared to the core role functions they were expected to perform.

"And that's quite right too, you need to get the check up out of the way first and I think if it [sex] had been something that had been right there from the start, I think if women wanted to ask then....
Researcher: Then they feel they would have permission to do so....
PT03: They would feel, they ought to feel that there is someone to ask and that this [sexual concerns] is part of the whole thing rather than something that's not even addressed...”

[PT03: 55 year old woman 8 months post surgery / radiotherapy for endometrial cancer]

"Because I think it affects people differently. You know, if I hadn't had a problem I don't think I'd want, you know, that wouldn't be on my list of questions that I'd want the doctor to ask me I suppose, on my check ups.”

[PT20: 33 year old woman 22 months post chemo-radiotherapy for cervical cancer]
"Because I've been hanging around the doctor's clinics and it's [sexual concerns] not something they talk about, it's as if it's irrelevant. Why are you thinking about that? We're saving your life. But then you think, what kind of life is it going to be if they are going to feel completely cut off, isolated, infectious, sore?"

[HCP17: Female therapy radiographer]

"Because in [cancer centre] there's not a huge emphasis on feminine care during radiotherapy....They don't have any dedicated nursing staff or radiographer staff to, you know, be aware that patients are using their dilators, how are you using them, are you, you know, okay with that? I think that's one of the problems and if the radiographer staff are not prompting us, we don't think about it. And, you know, because most of the patients don't raise it [sexual concerns] you don't really know, you know, the impact on people's lives.”

[HCP13: Female specialist registrar]

Some women concluded that health professionals did not consider their sexual well-being an important aspect of their recovery because of the rarity with which practitioners asked questions about their experience of sexual difficulties. Six women and one partner remarked that they had never been asked questions about their sexual recovery; while one commented on the inadequate level of content within written patient information booklets she had been given. Two women specifically commented that they felt their medical follow up was very physical or biomedical in its focus, with no emphasis being placed on their emotional or psychosocial well-being.

“No I honestly don't remember anybody saying anything about any form of [sex] apart from [staff nurse name] again who probably said 'Are you using your douche?' and, you know, everything is fine. And when [consultant name] does the internal he, he sort of has a look and says everything's fine and nothing is collapsing from that point of view, but not from a sexual one, no.

Researcher: If you think of the sexual elements of your relationship, if you felt it wasn't where the two of you wanted it to be, would you feel you could approach your treatment team about that?

PT11: it is quite difficult. I don't think, I don't think it would have occurred to me to approach the treatment team, to be honest.”

[PT11: 59 year old woman 12 months post surgery / chemo-radiotherapy for cervical cancer]

“And the booklets, I mean there's nothing in them to read, on sex there's two paragraphs. You know, there's nothing in here.....I mean even in this one on the feminine care there is so little information there...”

[PT14: 63 year old woman 4 months post surgery / radiotherapy for endometrial cancer]

The limited focus within medical follow up on psychosocial and psychosexual aspects of women's recovery post-treatment is endorsed by participant observation findings
presented in chapter five. While the women assumed practitioners accorded treatment induced sexual morbidity a low priority because of its omission from follow up consultations, health professionals were more likely to cite specific circumstances when they were unlikely to raise the topic of sexual dysfunction in a woman's consultation. Practitioners were less likely to address sexual concerns with women because of their focus on excluding disease recurrence and where the woman's prognosis was poor or she appeared to be physically frail. These findings from interviews with health professionals are also supported by findings from the participant observation data of this study.

"And then involvement up front of other people who are specifically trained in things like psychosexual issues would, would help enormously, there's no doubt, you know, because no matter how good it gets we will still be limited by concentrating on recurrence only and by time, you know."

[HCP03: Male clinical research fellow]

"HCP15: When you know the prognosis and the patient....that's it, I don't mention it [sexual issues].
Researcher: Right, fair enough.
HCP15: I had a few, quite a few, they were young girls but the prognosis was really bad and they die very quickly, so they went through the motion of treatment that obviously didn't work and I didn't talk about sex with them."

[HCP15: Female outpatient staff nurse]

Only one doctor [HCP 03] commented that the lack of specialist training about this particular aspect of treatment related morbidity may act as a barrier to being able to discuss sexual morbidity with patients. The lack of specialist training related to treatment induced sexual morbidity is discussed in section 9.4 of this chapter.

9.1.3 Patient Characteristics

The patient characteristics mentioned by health care professionals or by patients and their partners that acted as a barrier to the discussion of sexual concerns in the clinic are summarised in figure 9.3. As discussed previously, health professionals felt that sexual concerns were far less likely to be discussed with older women (n=16). When pressed to state an age at which a woman may be considered older, and thus less likely to be sexually active, most health professionals felt this would apply to women over 70 years of age although some were reticent to discuss sexual morbidity with women over 60 years. While it could be argued that the sample of women taking part in this study may have a particular interest in their sexual well-being, it was interesting to note that patient
participants included two women (PT06 and PT15) over 70 years of age and a further six women over the age of 60 years (PTs 04, 07, 10, 14, 17 and 19). Only two women interviewed in the study (PT11 aged 59 and PT 15 aged 70) felt that their age may have been a reason for not being asked by health professionals about their sexual recovery post-treatment. The influence of patient age on discussion of treatment related sexual concerns has already been fully explored in section 7.3.1 of this thesis.

Figure 9.3: Comparative frequency (%) of patient characteristics identified by health care professionals or patients / partners as barriers to communication about sexual difficulties in the clinic

As can be see from figure 9.3, another patient characteristic that acted as a barrier to the discussion of sexual issues from the perspective of health professionals was the woman’s ethnic or cultural background and religion. Eight health professionals stated they found it more difficult to discuss sexual issues with women from ethnic minority communities, in particular women from Asian or oriental cultural backgrounds and those who were of Muslim faith.

“I mean a particular group of patients that I sometimes feel it can be more of a problem with, are the….particularly patients who come from, you know, the Middle
East, or people who are veiled. And you know that there are big issues, well they are not issues, but you know there's a cultural, you're sort of, well I'm not so familiar with the culture really and you know what I have in the back of my mind is, you know, maybe these people tend to be more private with their lives. 
...I have to say I do feel slightly more inhibited with people from that culture and I wonder whether, when I've got the husband and the woman there I sometimes feel hmm, is this a real taboo for me to bring this[sex] up? I really don't know."

[HCP05: Male specialist registrar]

"I think the Muslim population is very reticent about discussing any sexual problems and they tend to be dominated by their husbands who make the decisions for them. So that's a group that I think are very difficult to talk to. But that's the only group that I would particularly accept are [difficult to talk to]."

[HCP20: Female consultant clinical oncologist]

"But certainly the few ethnic patients that I've had I haven't been able to [discuss sexual issues] because one, there's been a language barrier. Often they are interpreting through male relatives and that was certainly the experience of the last couple of Asian ladies and it was very difficult. And clearly, you know the interpreter didn't want to ask her and neither did the person who was being interpreted for."

[HCP19: Female consultant clinical oncologist]

The reasons given for these communication difficulties were that they experienced these women as being more embarrassed by the subject of sexuality and that communication attempts were often blocked either by the woman's reticence to reply or by language barriers. Within the sample of women who were interviewed for this study there were only two women who were not white Caucasian, one was a woman from Afghanistan and the other was from Zimbabwe.

With regards to religious background, only one of the patient participants (PT18) was a practising Muslim and she did not consider her faith a barrier to the discussion of sexual issues. As discussed earlier in this chapter, the only patient (PT24) who cited her religious upbringing as a specific inhibitory factor in being able to discuss sexual concerns with male members of her treatment team was a practising Roman Catholic. It was not possible to compare the views of women and health professionals regarding the contribution of ethnicity and religious backgrounds to communication difficulties regarding sexuality as there was insufficient diversity within the patient sample.

Seventeen health professionals and nine women agreed that embarrassment on the part of the woman would act as barrier to the discussion of sexual concerns in the clinic, with the majority of participants simply stating that feelings of embarrassment were inherent to the discussion of sexual matters.
“**Researcher:** And when he was asking did it embarrass you to be asked about it [sexual morbidity]?

**PT08:** Slightly. Because he is so gorgeous. [Laughing] You know, really I think that’s, I thought ‘Oh dear!’ Ehm, yeh, I was a little embarrassed.

**Researcher:** Did you perceive that he was embarrassed asking?

**PT08:** No. No he was very medical about it. Er, no he was fine, it was me.”

[**PT08:** 58 year old woman 6 months post chemo-radiotherapy for anal cancer]

“It [sex] is a very sensitive issue. A lot of women I am sure when they have questions in mind, they might be embarrassed, there is an element of embarrassment to ask these questions.”

[**PT18:** 46 year old woman 6 months post surgery / radiotherapy for endometrial cancer]

One patient felt her embarrassment emanated from the fact that she felt she should simply be grateful that her cancer had been successfully treated and that it would be inappropriate for her to consider her sexual well-being important within this context.

“Obviously afterwards, you know, six or seven months afterwards you do start to think, well, especially for [husband’s name] and what have you and the need [for sex] would be there for me still. But I was just, yeh, there was just no way that I would contemplate it. I didn’t know who to talk to about it. Well there isn’t, and you feel a little bit, I would feel ridiculous I think, ehm, because you are lucky to be alive. I mean why would you think that [sex] would be important at that stage, do you know?”

[**PT22:** 51 year old woman 31 months post surgery / radiotherapy for cervical cancer]

A number of women (n = 10) felt that one of the reasons they were unlikely to ask their treatment team about sexual issues was that they lacked the knowledge of what sexual difficulties may be experienced in association with their treatment and often waited for sexual changes to return to “normal” in what they considered to be a reasonable period of time post-treatment completion.

“Well no, because I thought perhaps it was just a normal thing, you know, perhaps it was just normal that you just sort of go off sex for a little while and, you know, it’ll come back or whatever, ehm, and it never really entered my head to ask anybody. As you say, no-one asked me about it so I didn’t even bother to ask anyone about it.”

[**PT07:** 63 year old woman 12 months post chemo-radiation / surgery for rectal cancer]
A potential source of distress for these women and their partners was that having waited for some months for their loss of sexual desire or dyspareunia to improve they were then faced with a persistent or more complex sexual difficulty to overcome.

"I think they [medical staff] should say to you like 'You are going through this treatment and your sexual would go off quite a bit obviously but then after it [sexual desire] could take up to a year to come back, if you have any problems then discuss this so maybe long term we could work out what is the problem.' I think they should tell you that long term. And then people won't keep, like me, won't ask,...because you don't ask, you keep thinking 'Well maybe it will come back, oh it will come back next year.' Whereas if you knew that and you say 'Well look, I've been out of treatment six months and I've got no sexual activities, is there anything wrong?' I mean, what can be done? And that way you can ask earlier, I think so."
[PT02: 51 year old woman 12 months post chemo-radiotherapy for anal cancer]

"I think to be honest I was totally stunned after the operation when, when I really knew then that was the end of our sex life, basically. I think I found, I never, I didn't realise it was going to be that, you know. And I don't know if [wife's name: PT07] case is unusual, because of this vagina business [resection of posterior vaginal wall]. It wasn't explained that that could happen beforehand which, maybe, I mean I'm not blaming anybody, I'm not criticising anybody. Perhaps when the surgeon done the job that's the only way to do it and perhaps that doesn't happen to everybody but.....no, if it hadn't happened I feel we could be back on to a sexual relationship, a full sexual relationship. But I don't know that there's anything more you can do other than perhaps to warn people that these sorts of things can happen."
[PTNR03: >60 year old husband of PT07: 63 year old woman 12 months post chemo-radiotherapy / A-P resection for rectal cancer]

This couple (PT07 / PTNR03) were unable to resume sexual intercourse due to the severe vaginal stenosis that had developed as a result of both radiotherapy and vaginal wall resection. There was a delay of over ten months in health professionals becoming aware that the stenosis had occurred in the absence of routine vaginal examination, a lack of health practitioner enquiry about vaginal dilator compliance or sexual recovery and compounded by this woman's reticence to raise sexual concerns with her medical team.

There was broad agreement between health professionals (n = 10) and women (n = 12) that sexuality was often accorded a low priority by the women themselves. Predictably nine of the women placed sexual well-being low on their list of priorities during acute cancer treatment, particularly when the long-term control of their cancer was not yet assured.
“I mean I did touch on it [sex] occasionally but I didn’t talk about it a great deal. I think the other side effects were more overwhelming, the tiredness in particular, and how slow I felt and you know, how exhausted I was really was the overwhelming experience more than anything......I had about another three months kind of like recovery period before I went back to work. And in that time a lot of my emotional issues and the big changes that I wanted to make in my life were much more prominent in my mind and my focus of attention was really on those things. Whereas probably my sexual identity and my sex life was probably the bit at the bottom of the pile of my priorities really, it wasn’t kind of a big issue.”

[PT12: 42 year old woman 14 months post chemo-radiotherapy for cervical cancer]

“Researcher: I mean how do we know if it’s the right time to ask a woman, or whether it’s too early?

PT13: With me, because I finished, it’s been a year since I finished my treatment I think I feel it’s the right time. But had you asked me when I was having my treatment, I think that was a secondary concern. My focus was on getting better and sex was something I wouldn’t even dream of at that stage, so maybe asking after the treatment would be better.”

[PT13: 32 year old woman 16 months post surgery / chemo-radiotherapy for cervical cancer]

This may mean that questions about sexual well-being are less likely raised by women in the early months post-treatment, but that sexuality may increase in relevance once a women’s long-term survival appears more certain.

Only a minority of women (n = 2) and health professionals (n = 2) believed that women without a current partner would be less interested in discussing sexual morbidity.

“I suppose when you look at their history, sometimes you’ll read and they’ll be in their fifties, early sixties, they are single, they’ve never married, they’ve not had kids, then you might, and they are a bit awkward about being examined.......then you might not bring it [sex] up and that doesn’t, you know that, I suppose that’s maybe a prejudice coming in then but that would be a time when you wouldn’t necessarily bring it up.”

[HCP06: Female specialist registrar]

“But as the time hasn’t arisen yet for me to meet anybody I don’t think there will be. Sex was not my priority. If I’d been living with a husband that would have been entirely different, like you see some of these people.”

[PT04: 64 year old woman 8 months post chemo-radiotherapy for cervical cancer]

“Perhaps I indicated that I wasn’t in a relationship but certainly there were no questions asked about [sex], it was taken for granted if you weren’t in a relationship
that you weren't sexual in any way, so it certainly didn't deal with the problem of sexuality with people who are on their own.”

[PT17: 67 year old divorced woman 15 months post chemo-radiotherapy for bladder cancer]

An interesting comment made by four health professionals but none of the patients who took part in the study was the extent to which they felt that sexual expression or well-being was less important to women compared to men both in general and for individuals having cancer treatment.

“Researcher: Do you get a sense when you’re with these women that it’s less of a priority for them than it is for the equivalent male patient?

HCP08: I think one tends to get that impression, yes, and you get the impression because quite often you are talking to males with their wives present, when it’s the male that’s the patient and you know you say this, that and the other but the wife will say ‘Oh we don’t...doesn’t matter, not to worry.’ Which gives you the impression that probably, you know, these things [sex] are a different priority for women, you know, you think they are not a priority but they have a different place.”

[HCP08: Female consultant clinical oncologist]

“I think in my experience of the rectal patient, without a doubt the men raise it [sexual concerns] more than the women.”

[HCP10: Female clinical nurse specialist in colorectal cancer]

Furthermore, two health professionals noted that some of the women they had treated used their cancer diagnosis and treatment as an excuse to cease sexual relations with their husbands, particularly where the relationship was less than ideal to the woman.

“I am also acutely aware of the pressure that women are under, or some women are under from their partners and so I will be quite careful...... I’ve come across a few relationships that have not been ideal in the past and I’ve been quite careful not to put somebody under pressure to have intercourse because quite often they [women] can physiologically and they don’t want their partner to know...not quite often but it’s not uncommon.”

[HCP09: Female clinical nurse specialist in gynae-oncology]

“And so the people that are closed [about sex] generally, perhaps in their forties and fifties, I mean some people use it as a way of not ever having sex with their husbands again.”

[HCP16: Female therapy radiographer]

9.1.4 Illness and Treatment Characteristics

As mentioned in chapters six and seven, the nature of cancer and its treatment creates a particular frame of reference for the discussion of sexuality for both health professionals and patients. Understandably sexuality is usually accorded a lower priority in the context of
illness than in health, suggesting that cancer may not yet be viewed as a chronic illness but one that continues to pose an existential threat to the individuals affected. Clearly within the culture of the oncology follow up clinic both health professionals and patients are focused on ensuring physical recovery from the acute side effects of treatment and on ensuring that any disease recurrence is detected with a minimum of delay. Both health professionals (n=11) and patients (n = 10) felt that the emphasis placed on survival and coping with the burden of the illness and acute side effects of treatment during follow up was an important reason why sexual issues were not a priority for discussion within the consulting room.

"And I think it also depends on the environment that you're giving information in, because if you're giving information in an environment where the patient's come back, they've got a new symptom, they are worried about relapse, you know, and you know, a patient comes in very stressed, very anxious, then it, I don't think it's necessarily appropriate at that stage because I think, actually, although sexual issues are very important to patients, they come through the door in many ways with a similar agenda to you have, the top of their tick box.....has it [the cancer] come back?...."

[HCP05: Male specialist registrar]

"I'm sure there is some group of physicians who will just, you know, OK we've treated your disease, we've managed to potentially cure you of your disease. Yes, there are long term complications but there's nothing much we can do about it and, you know, these things [sexual difficulties] sort of happen and yes you can mention them, and yes we can empathise with you but you know it actually makes our job more difficult because we may not be able to do something about it......But you know that your treatment, or potentially your treatment has sort of caused this problem and, er, I think, you know, it's something generally speaking that isn't dealt with that much, and also especially on a basis when you're, when you're talking with your colleagues as well....Oh well, you know, this patient's come up with such and such a [sexual] problem etc. and it's not something you talk freely about with your colleagues. And a lot of it at the end of the day is just something that's pretty much pushed under the carpet, because patients will push it under the carpet and then you will go 'Naw, if they've pushed it under the carpet I shall just push it under the carpet as well!!"

[HCP14: Male specialist registrar]

Follow up clinics focused predominantly on the resolution of acute treatment side effects arising from pelvic irradiation and concurrent chemotherapy, such as skin excoriation, nausea, and bowel and bladder disruption. Both health professionals (n = 10) and women (n = 9) agreed that where there were active clinical problems to explore and resolve, sexual issues were less likely to be discussed in a consultation (see figure 9.1).
"...And patients on radiotherapy, I would think, just want, or I get the impression just get me through this, especially if they have low rectal tumours. They really, the skin soreness, diarrhoea, skin soreness, urinary problems or the pain when they pass urine, that's really what they seem to want to focus on. I might be totally wrong but I think once they have finished treatment I don't know that we address it [sexual concerns]. So it's a whole new set of doctors again and the worst in all of this I think is that we don't document it....so there isn't even if they read the notes there isn't, and it's something very private, I don't know how the patients will feel about documenting a private conversation as part of your assessment..."

[HCP10: Female clinical nurse specialist in colorectal cancer]

"I think because there was so much going on it didn't cross your mind, you were too busy worrying about, I think the main thing you was busy worrying about was having the treatment and was it working? I don't think anything else sort of thought, would it affect me having sex, this that and the other, you know what I mean, never ever thought. Never even asked if you could have sex actually, never thought about it. I don't think a lot of people would."

[PT02: 51 year old woman 12 months post chemo-radiotherapy for anal cancer]

It was also interesting to note that treatment related sexual difficulties did not appear to be discussed or defined in the same way as the functional disruptions to patient's urinary or gastrointestinal systems by either the health professionals or the women themselves.

"I think it's not just as a clinician do we feel more comfortable talking to patients about the bowels and bladder, patients feel more comfortable talking about bowels and bladder.....It is something around there's a, that being a slightly unknown area for everyone and, you know, you kind of know that everybody's got to poo and pee but you don't know what everybody has to do with sort of sex, you know..."

[HCP08: Female consultant clinical oncologist]

Unlike bowel and bladder late effects, sexual difficulties were not a daily occurrence that interfered with the resumption of normal work and social related activities. Nevertheless, as discussed in chapter 8, sexual difficulties could still be a source of distress to the women and couples affected.

One final illness related factor that appeared to reduce the likelihood that sexual concerns would be discussed in the clinic was the primary site of the woman's cancer. While none of the seven women with rectal or anal cancer appeared to be aware of this issue, eight of the ten health professionals who treated lower gastrointestinal malignancies felt that there was a lower awareness of the prevalence of treatment induced sexual difficulties in this group of women than among those with a gynaecological diagnosis (see figure 9.1).
"No I don't think they [women] think about it [sexual effects] at all 'cos they don't understand the radiotherapy goes through the vagina, they just think it goes immediately to the tumour and they don't understand about, unless you explain, they don't understand that it will affect the bladder and that, you know, so when I explain that I usually say well because the rectum sits so close to the vagina or because it sits so close to the bladder you will get side effects from the bladder and then they're like 'Oh, right!'. They understand.........I mean I remember thinking it was only gynae patients that had that [sexual] problem until I did my exam and I was like....Oh, rectum and anus.....yeh. I didn't realise before, I don't think it's that well known to be honest.”

[HCP01: Female specialist registrar]

"Researcher: And the nature of the primary site....do you think that in any way affects the profile of sexual issues?
HCP03: Absolutely, definitely. Without a shadow of a doubt. Because you can, if you are seeing someone after endometrial or cervical cancer it's almost impossible not to address sexual issues. I mean, and also you always do a PV and you, you're often inhibited in your assessment by, you know, strictures in the vagina so it absolutely does, without a doubt, yeh. But you can do a good medical-type assessment and miss out sexual issues completely, but with a gynae exam it's very hard to, you know.”

[HCP03: Male clinical research fellow]

As discussed previously in section 7.4.2, women with rectal or anal malignancies did not receive a routine vaginal examination after pelvic radiotherapy and clinicians working with these women appeared less confident and knowledgeable regarding the types of sexual difficulties likely to affect these women than clinicians working with women treated for cervical or endometrial cancer.

"HCP13: ...whereas the kind of rectal cancers, female rectal cancers, I do sometimes forget, you know, kind of addressing that issue [sexual concerns] and you know, we know it could be a side effect as well and ehm, fertility, for example is something we don't routinely consent for in rectal cancer patients.
Researcher: Right, but you would in gynaecology?
HCP13: Yes, yes.”

[HCP13: Female specialist registrar]

Indeed, it was not uncommon when a sexual difficulty had been elicited by a health professional for women with rectal or anal cancer to be referred to the gynae-oncology nurse specialist for clinical advice. This was because there was insufficient expertise regarding female sexual morbidity among the medical and nursing practitioners caring for those with lower GI tumours.
9.2 Factors that enable the discussion of treatment related sexual difficulties with women

In contrast to the large volume of textual data that explored barriers to communication about treatment related female sexual difficulties experienced by health professionals, women and their partners, analysis of interview transcripts revealed a paucity of data that spoke of the factors participants found helpful in supporting discussions about sexual concerns within clinical encounters (see figure 9.4).

Figure 9.4: Comparative frequency (%) of factors identified by health care professionals or patients / partners as enabling communication about sexual difficulties in the clinic
As can be seen from figure 9.4, four health practitioners, three women and two male partners felt the discussion of sexual concerns was more likely to occur when women or couples themselves raised the topic.

"Researcher: To what extent do you find women bringing up the topic spontaneously? Does it happen very often?

HCP06: It doesn't happen, well I've had a few that have quite big concerns about it that bring it up and it dominates the consultation. The way they bring it up, it's usually at the four weeks appointment after radiotherapy they ask, if they've not been given dilators or spoken to about, they ask about it and then that can be your way in [to talk about sexual concerns]. So then you know that that's something they probably want to discuss, but that tends to be the way they [women] bring it up rather than directly asking." [HCP06: Female specialist registrar]

"And sometimes surprisingly you find that at that first, that three month follow up they [women] are then effectively asking you for permission to go back to having intercourse." [HCP19: Female consultant clinical oncologist]

"Researcher: And when you initiated that discussion, how did you find the response you got both in terms of content and it terms of comfort in the discussion that ensued?

PTNR04: Well the first time we raised it [painful intercourse] it was quite straightforward. They said 'Oh well it won't get better and we have to, you must keep trying', so it was quite matter of fact, quite straightforward, just a straightforward piece of advice." [PTNR04: 51-60 year old husband of PT16, 56 year old woman 24 months post surgery/radiotherapy for endometrial cancer]

However, seven women stated a preference for health professionals to be more proactive in asking them about sexual recovery.

"Researcher: Would you have felt that the follow up clinic was the right context for asking questions about sexual concerns, for example?

PT12: I felt the follow up clinic was. I would have liked it to have been. I would have liked people to have raised it with me.” [PT12: 42 year old woman 14 months post chemo-radiotherapy for cervical cancer]

"It is a very sensitive issue. A lot of women I am sure when they have questions in mind they might be embarrassed, there is an element of embarrassment to ask these questions. And I think it should come from the medical team, just to approach, not directly, but just to bring this topic indirectly to the discussion. I am sure women will then have the courage to talk about it. Because if we ask some women may not like to talk about it and some women would like to talk about it but they are not confident. So I think it comes from a medical team support, indirect talk, and then I think the discussion will be open and there will always be room to discuss the sexual issue.” [PT18: 46 year old woman 6 months post surgery/radiotherapy for endometrial cancer]
Although findings from participant observation of follow up clinics found no relationship between the gender of the practitioner conducting the consultation and the likelihood that sexual issues would be discussed during consultations (chapter five), in interviews four female doctors, one male doctor and three women specifically stated that they found same gender consultations a more conducive context for the discussion of treatment related sexual concerns.

"Researcher: Do you think it makes a difference the fact that you’re a woman, in terms of the ease with which you can actually address sexual concerns with other women?
HCP06: Yeh, I think so, because certainly they sort of, when you examine them they go ‘Oh thanks, great, it’s nice to see a woman’, because the previous two appointments they’ve been examined by a man so they are quite sort of relieved from that point of view. And I think they sort of, they are more likely to bring it [sexual concerns] up with me than they are with the male registrar, I am sure. And for a male doctor it’s probably, they probably have to think about it more maybe how they bring it up without it sounding too, ehm, not too direct. But maybe some women may be a bit uncomfortable but then saying that, I think the majority of women are used to being examined by male doctors because up until recently most doctors have been males." [HCP06: Female specialist registrar]

"Researcher: Does it matter if the person you are meeting with is a woman or a man? Does that influence whether you feel comfortable or not?
PT13: Ehm, personally I think I would feel comfortable talking to another woman.
Researcher: Another woman.
PT13: Woman, yeh, than talking to a man. I feel like they [male doctors] don’t understand what I will be talking about." [PT13: 32 year old woman 16 months post chemo-radiotherapy for cervical cancer]

In contrast to conflicting findings regarding the potential influence of health practitioner gender, there was concordance between participant observation (section 5.3.1) and interview data in relation to the influence of women’s age on the discussion of sexual concerns. A number of clinicians stated they found it easier to raise questions about treatment related sexual difficulties when their female patients were of a younger age (n = 10) as they assumed these women were more likely to be sexually active prior to their illness and treatment.

"I mean some patients will bring up psychosexual things themselves, ehm, generally they're younger patients, but not always. Sometimes old ladies will give you hilarious accounts of what they would or wouldn’t want to do. Ehm, usually quite unrealistic, but nevertheless it tends to be the younger ones who bring it up themselves.” [HCP02: Male consultant clinical oncologist]
"If they are particularly young then I will tend to ask about intercourse, you know if they get, if they are in a relationship and if they are having intercourse and if there are problems with that, but I tend to, I do tend to do that more with the younger age group. I wouldn't necessarily do it with the older age group and I always give them opportunity to ask me questions so I tend to ask an open ended question and see what, what they [older women] bring up.....But if they are under sixty then you would be more happy to ask the question."

[HCP06: Female specialist registrar]

None of the women interviewed, sixteen of whom were under the age of 60 years and six under the age of 50 years, commented that their age had any influence on increasing the likelihood that sexual concerns would be raised in clinical consultations.

Four medical practitioners working within gastrointestinal oncology felt they were more likely to ask women about their sexual recovery because women being treated for rectal and anal malignancies were taking part in clinical trials where structured questions about vaginal and vulval toxicity and female sexual dysfunction were a formal research documentation requirement. Furthermore, three medical staff (one from gynaecology and two from gastrointestinal teams) stated that they found the use of structured consent forms, when specific treatment toxicities were listed and had to be discussed with women, was also a way of raising the profile of sexual morbidity particularly among women treated for rectal or anal malignancies where, as has been discussed previously, vaginal examinations were not a routine aspect of physical examination in the clinic and the profile of female sexual dysfunction was lower than it was within gynae-oncology follow up clinics.

"....Trial patients I suppose, you know, you are fully rigorous with the follow-up because you have to be. For non-trial patients I'd have to admit to not asking about sexual, ehm, questions as often as I should........You know, I mean the ideal is, I mean the research patients everything is discussed because you have the toxicity form. And what people at home [HCP03’s previous place of work] have, which is the way it should be everywhere I think is a standardised form for non-research patients. Otherwise it [sexual morbidity] just won’t be discussed."

[HCP03: Male clinical research fellow]

"....I think also it's not, those forms are terribly useful as prompts to the staff which is usually medical staff taking the consent, so I think it's not just from the patient's point of view in terms of having it [treatment side effects] in black and white but the doctor will probably forget to mention it [sexual difficulties] in those various aspects of it unless it's there......so I think we could look at that."

[HCP08: Female consultant clinical oncologist]
Health care practitioners (n = 17), patients and their partners (n = 13) appeared to agree that the single most important factor determining whether or not sexual concerns were discussed within follow up consultations was the rapport between patients and practitioners.

"I think it's always towards the end of the consultation, I think that either for you to bring it [sexual concerns] up or for them [women] to bring it up they have to have built a rapport with you. Umm, I think it's usually me that would bring it up and then as soon as you mention it then they'll talk about it....freely. I think if they've got a [sexual] problem then they're quite relieved to talk about it.....but then if they actually want to be sexually active and have a problem then I think they are quite grateful that you've asked and quite willing to talk about it and hoping that you can do some good."

[HCP01: Female specialist registrar]

"I'm feeling my way a little bit as to how much they want to disclose [about sexual concerns] and sometimes when I ask questions I think 'I'm not sure if this is going to, you know, sound right to them because this might, sort of, freak them out. So I guess I feel in myself I need to have that relationship or that rapport and feel that I can, I've got that before I can perhaps explore what I need to explore. In some people you get that instantly and some people you have to work on that."

[HCP04: Female clinical nurse specialist in gynae-oncology]

"[First name of woman's consultant] did, she just sort of asked me I mean, you know, we had a friendly, frank relationship and she just asked if, you know, I was sexually active and I said 'Yes' and 'Any problems?' and I said 'No' and, you know, just told her that the [vaginal] opening was smaller I think and that we weren't having any problems. Ehm, I don't think we went into it [sexual issues] in any depth because it wasn't an issue for me so she didn't pursue it."

[PT09: 50 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

"I say I am lucky with my GP....yeh, he said I think it's got to be surgery. Because obviously things were not getting back to normal so he, he's you know, fantastic, very, very good doctor. And as I say perhaps easy to talk to in a way...."

[PT23: 58 year old woman 29 months post chemo-radiotherapy for anal cancer who consulted her GP because of severe vaginal stenosis]

Where communication between health professionals and women was flowing well and embarrassment was minimal then participants felt able to address the more personal and sensitive aspects of women's recovery after pelvic radiotherapy.
9.3 Developing personal strategies for “sexual talk”

Analysis of the barriers to communication about treatment related sexual concerns within the clinic suggest that broaching the topic of sexual morbidity was universally considered to be a challenging communication topic for health professionals and patients alike. As a result, when practitioners considered the need to discuss sexual issues with women, a number adopted personal communication strategies designed to make discussion of this sensitive topic more acceptable and less embarrassing for both themselves and the women they were reviewing in the clinics.

These communication strategies were either a general approach to the discussion of sexuality, such as the use of humour, or the use of specific clinical topics to legitimise its discussion through a direct link between radiotherapy induced infertility, menopause or vaginal toxicity and sexual morbidity.

Four practitioners mentioned the use of humour to break the ice and reduce embarrassment that could be caused by the discussion of sexual issues, although this was not a strategy mentioned by any of the patients interviewed for the study.

“Although his style of talking to patients is very different from mine, it’s a style that can work. And I think particularly he works with the more middle aged and older women and a lot of it is done through humour. Which is a way of talking about psychosexual things, to do it through humour, and I do sometimes myself. Ehm...because it sort of breaks the barrier a bit.”

[HCP02: Male consultant clinical oncologist]

“...if you can sort of, in some ways, you know, bring it up in a slightly jocular way, just sort of fairly light way, then you can plough into depth and it can change the tone, but it is often something that, you know, has to be introduced quite sort of lightly.”

[HCP08: Female consultant clinical oncologist]

Fourteen health professionals mentioned specific clinical topics they used to lead on to the discussion of sexual recovery during follow up clinics. Three practitioners used discussion about treatment impact on fertility or the induction of early menopause to lead to discussion about potential sexual side effects of pelvic radiotherapy.

“I think if it’s a young patient who maybe is pre-menopausal then I’m much more likely to ask [about sexual issues] probably by going through the menopausal symptoms first and then moving on to the sexual side.”

[HCP01: Female specialist registrar]
Six of the eleven doctors interviewed found it easier to address sexual concerns associated with signs of vaginal toxicity that they were aware of or had specifically elicited during vaginal examination (gynaecology clinics only).

“Yes. I mean usually it [vaginal examination] would be an assessment for recurrent disease in any event. But it’s also an indication about sexual function as well, so eh, clearly if someone’s got vaginal stenosis and some of the elderly patients have, then, eh, I would be watching out for that or, or asking about it and that might prompt questions about sexual function.”

[HCP18: Female consultant clinical oncologist]

It was unusual for practitioners to ask direct questions about sexual recovery and a number of practitioners preferred to talk about what they perceived to be less sensitive topics earlier in a consultation, such as bowel and bladder toxicity thus encouraging rapport and trust to build before addressing vaginal toxicity and linking this to asking about sexual morbidity later in the consultation.

“So that’s often, that’s why I say my initial questions I ask them about the bladder and about the bowel and then often I start talking and also I think you’ve got a bit more, slightly more rapport with them as you come towards the end of the interview. So I often find myself in a situation after I’ve examined them you know, and then like it’s very uncomfortable and you say ‘You’ve got adhesions, did you use your dilator, did you do this, are you sexually active?’....And then you often find that once you’ve opened up the subject, if people want to talk about it then they will. It’s like I was telling you about this lady I saw in clinic....She hadn’t mentioned any of this at all, I said are you well, everything fine, blah, blah, blah, everything was fine. I examined her, she had quite a lot of bleeding and then when I asked her ‘Oh well’, she said, ‘Actually I’ve been getting quite a lot of bleeding after intercourse but I didn’t want to ask anybody about it. And then it opened and I could say to her ‘Well, you know, you have adhesions and this is quite common’ and so forth, and then at that point she was like ‘Oh yeh, and it’s also very dry’ and then the whole conversation opened up, you see.”

[HCP05: Male specialist registrar]

Other practitioners used strategies such as normalising sexual difficulties as yet another treatment side effect or de-personalising sexual changes so that women were less self-conscious about their personal experience as they were more aware these difficulties were prevalent in all women treated by pelvic surgery and/or radiotherapy.

“Researcher: So if you were conducting an interview at what point would the questions around sexual issues come in?
HCP06: It would probably follow after the bladder and bowel question, yeh and to put it in as a so it seems, so it seems as if a normal question, so I’m not trying to
make it too much of an issue so that hopefully if they want to discuss things they will. Eh, yeh, so that tends to be when I’ll place the question.”

[HCP06: Female specialist registrar]

“I try very hard in the beginning to make it non-personal to them so I might say, rather than saying have you found a problem I try, actually that’s the other thing I try really hard not to use the word ‘problem’. I try to say something like ‘Some ladies find after having radical hysterectomy they have, because of the nerves that have been cut, have problems attaining a climax. If that is a problem for yourself in the future then, you know, so I try and de-personalise it and then they might say whatever….. I try and be quite general in the beginning.”

[HCP04: Female clinical nurse specialist in gynae-oncology]

Of the nine nurses and therapy radiographers that took part in the study (seven nurses, two therapy radiographers), five used the discussion of vaginal douche and dilators with women to lead them on to a discussion about the resumption of sexual activity post-treatment to varying degrees.

“Some of them will come, you know, after their treatment, when they come to collect their dilators they talk to me, they say ‘Oh I forgot to tell the doctor, you know, I tried to have sex with my husband and, you know, it was painful and we couldn’t do it.’ Then I can discuss about that I say ‘You know that is why you’ve got to use the dilators to help you and during intercourse you can use your KY jelly because it is only water based, it hasn’t got anything to irritate the vaginal wall so, you know, we talk a lot about them.”

[HCP11: Female radiotherapy department staff nurse]

“You’ve got a dilator. No, first you’ve got the douche. And they [women] say ‘The douche is hard and not comfortable’ or whatever, or they are too tired to use it, if it’s [the woman’s vagina], then you start to go, you know, how is the sex life?”

[HCP15: Female out-patient staff nurse]

Four of the eleven doctors who took part in the study also used the discussion of compliance with vaginal dilators as a means to enquire about any sexual difficulties women had encountered, particularly in the early weeks post-treatment where women may not yet have attempted to resume sexual intercourse.

“HCP01: I would use that saying we would normally recommend you use dilators and then explain because there’s a risk of long term scarring which may cause vaginal narrowing. And go through that route, probably. Researcher: So again, sometimes you say you can use another vehicle for a way to actually address a sexual concern without having to be so direct about it. HCP01: Yeh…..because that’s not embarrassing to say that.”

[HCP01: Female specialist registrar]
"Especially at the six weeks because I think sometimes, you know, it's probably not relevant to talk about sexual intercourse at that time, and even at the three months it's sometimes far too early. But I try and lead in with the idea of whether or not they are actually using their dilators, ehm, and then might ask them if, if it's actually made sexual intercourse [easier], have they resumed sexual intercourse and I usually ask them a direct question."

[HCP19: Female consultant clinical oncologist]

Although the women and partners interviewed did not tend to specifically identify the use of these practitioner strategies to enable the discussion of sexual concerns within consultations, one woman who was also a qualified health visitor did state a preference for what she referred to as a "soft and indirect" approach to talking sex in the clinic.

"Women may not be able to talk about it [sexual concerns], but I am sure if the medical team approaches women, not directly, in a soft, indirect way...

Researcher: So what would be soft and indirect?

PT18: Well, soft and indirect means to create a friendly atmosphere and give the woman the chance to talk about sexual issues. If we just indirectly talk about radiotherapy, the side effects and so on and part of it the sexual issues and she might say 'Yes, I would like to ask'. We can't ask a woman directly about the sexual issue, but if you bring the side effects, how you start approaching about my urine and bowel and then....so women would like to open this once we start from the non-sexual issues of.....and I am sure once they have gained the confidence with the medical team I am sure who likes to know they will open their heart and they would like to talk about it."

[PT18: 46 year old woman 6 months post surgery/radiotherapy for endometrial cancer]

9.4 Learning how to address sexual issues in practice

Demographic data from health care professionals who took part in this study indicated that seven out of the eleven medical staff who took part in this study had received no post-qualifying specialist education related to women's health, gynaecology, mental health or psychological counselling, sexual health or counselling or communication training. Of the four medical participants who had received formal education, all had attended brief (one day) in-service training related to the development of communication skills, although the content of this training appeared to focus predominantly on breaking bad news and did not specifically address the discussion of other sensitive topics, such as sexual difficulties, in the clinical setting. Two doctors (one male specialist registrar and one female consultant) had attended sessions related to women’s health and the specialist registrar had also
received some brief training in relation to the sexual morbidity associated with chemotherapy and radiotherapy and mental health issues.

"Researcher: To what extent was sexual impact of cancer therapies addressed within either your experience or your formal training?
HCP06: None!
Researcher: Not at all? Really?
HCP06: I don't think anyone spoke, I think we might have had one lecture on a course, but I don't, we've never been directly discussed or talked about really, no.
Researcher: And the communication course you mentioned, I mean was the focus of that breaking bad news or?
HCP06: Yeh, it tends to focus on breaking bad news. It doesn't tend to focus...it didn't focus on other issues. I've not done one here [cancer centre] so I don't know whether the ones here would be slightly different, I am sure they would be, but that's [talking about sexual issues] never come up in communication skills training. It probably should really."   [HCP06: Female specialist registrar]

Two therapy radiographers also took part in the study and had received one day of in-service training from an experienced gynae-oncology clinical nurse specialist employed by their cancer centre, although the precise detail of its content was not elicited within these interviews. However, they had not attended any formal education and training related to treatment induced sexual morbidity and both expressed concern that suitable specialist continuing professional development (CPD) activities for therapy radiographers appeared to be in short supply.

"HCP16: It's not something radiographers feel comfortable to tackle at the very beginning, although there has been training for quite a few of the staff to talk about the implications of pelvic radiotherapy and sexual issues.
Researcher: Right, and what sort of training has that generally entailed?
HCP16: Ehmm, it's a session with the specialist nurse, she sets up an hour's session.
Researcher: That's the gynae-oncology CNS?
HCP16: Yes."   [HCP16: Female therapy radiographer]

"HCP17: So I think its [sexual morbidity] definitely something that could do with a bit more training, that there are the national guidelines but they don't really, I don't think they are really adequate.
Researcher: What do you think is missing from them?
HCP17: It doesn't address how personal it is. ....I'd say I don't feel I really know enough about it [sexual concerns] and I think that holds true for all the therapy radiographers. Ehmm, you certainly don't, you are supposed to do CPD, but there doesn't seem to be anything on offer....So a decent training course would be good."   [HCP17: Female therapy radiographer]
The nursing staff who took part in the study appeared to have the best access to continuing professional development activities, with six out of the seven nurses having attended a study day on communication skills; one radiotherapy department staff nurse had attended a study day relating to psychological counselling and one out-patient department staff nurse had attended a study day related to women’s health.

One of the clinical nurse specialists in gynae-oncology (HCP04) had attended a short course (three days) on psychosexual counselling while the other (HCP09) had a professional background in gynaecology and women’s health. Both practitioners felt that being comfortable with sexual language made discussion of this topic easier in the clinical setting.

“I really believe that the education, you know, in any context helps you to challenge and question and feel more confident in yourself anyway. And I have been on other very short specialist training courses, like I’ve done a psychosexual counselling course and it was only three days but I learned so much. I by no means think I’m a psychosexual counsellor but what I found out was what I didn’t really know. And the other thing I did was when I first started this job I went to speak to a psychosexual counsellor and actually spoke to him for hours, he was really, and he was very comfortable and what I noticed was that he was very comfortable with all this [sexual] language...”

[HCP04: Female clinical nurse specialist in gynae-oncology]

“Oh I mean it’s much easier I think if you come from a gynae background because you are just very familiar with, with all the words, all the language, you know, you can say vagina in company without, without being phased at all. So that helps and so the cancer side of it is immaterial, really, that’s just sort of treatment modality and disease. But the actual sort of, the sex organs are very familiar so I don’t.....I mean it does help to really know and to be able to visualise things I think, I do think it’s hard for junior nurses to be able to talk about it but mostly because they don’t really understand what was what.”

[HCP09: Female clinical nurse specialist in gynae-oncology]

Although both colorectal nurse specialists (HCP10 and 12) had attended study days related to communication skills, neither had received specific education input regarding sexual morbidity associated with cancer treatment. Of the three staff nurses providing feminine care (advice regarding the use of vaginal douche, dilators and the use of intimate lubricants) all had learned this aspect of practice from senior nursing or medical colleagues on the job, with none having any formal preparation for this aspect of supportive care. Nor were any of these nurses familiar with the scant evidence base
regarding this intervention, although one of them had heard of the recently published national guidelines on vaginal dilation for women receiving pelvic radiotherapy.

"Researcher: How did you become the practitioner who, you know, focuses on feminine care and can actually address these issues with women, because it's not an easy topic to address.
HCP07: I think it's a little bit of everything in that I've been qualified for over twenty years, I've done psychiatry before, I've done hospice work before, I've never been afraid of asking awkward questions. I can tend to sort of pick up those vibes and it, I think that whilst a lot of people can do that, it's just some of the information I suppose I picked up from the person who did this job previously, who has left us and I have it in the front of her feminine care folder, guidelines she's, advice that she's written of what we should say to people..."

[HCP07: Female radiotherapy department staff nurse]

"I think its confidence and, its confidence and logic because you Just have to do things and you have to learn how to do it yourself, you think about it, how would you do it, and you don't have to go to school to figure out how to use dilators, come on!"

[HCP15: Female outpatient staff nurse]

Most of the doctors in the study also appeared to rely on learning from their experience with patients, learning how to communicate about sexual issues through role modelling from colleagues and from keeping themselves up to date through self-study of the professional literature in their field.

"I think it's probably the experience that it is a problem for patients or that it is an issues, whereas previously I was just preoccupied with thinking patients who have a cancer diagnosis are concerned about their cancer, whereas really, you know, they are concerned about their normal life equally as much as you know their kind of patient history, and so I've come to understand that more after I've done a prostate job......And maybe it's because men think differently about sex than women, that somehow I understood how important sexual function is even in, you know, what I would consider as elderly....And it's then when I started asking them routinely about sexual function and I think that came later on in my training......it's only when you come to realise how upset they are and that their sexual life or relationship with partners has virtually broken down because of the things you've done to them, it's only then that you realise."

[HCP13: Female specialist registrar]

"Researcher: If you think of your professional background and training, to what extent do you think that influences how you develop your practice in terms of addressing more sensitive topics within medical follow up?
HCP19: I think there's no doubt that if you've, if you've worked for, you know, you sort of tend to take some of the skills from the people that you've worked for and you try and merge them and come up with a sort of a, sort of your own style as you say. And I think there's no doubt that if you've worked for some people that you've
felt have had a good way of dealing with some of these issues ehm, you sort of learn it on the job, really.”

[HCP19: Female consultant clinical oncologist]

“I think it’s fair to say I’ve had zero training in any kind of psychological management of patients having this kind of treatment [pelvic radiotherapy]. I think my approach would be what I would call the common sense approach. That this clearly matters a great deal to most patients, some patients more so, and therefore it is extremely important to explore these [sexual] issues with them.”

[HCP20: Female consultant clinical oncologist]

However, as two of the doctors commented, the scant opportunities to observe discussions about sexual concerns in the clinic setting may have undermined the practical benefit of role modelling beyond promoting acquisition of generic communication skills.

“When I was an SHO I can think of certain registrars who were really good about breaking bad news so I hope I’ve picked up their technique. Whereas other people you’d think ‘God, I’d never do it like that.’ And you learn your own way. And I think probably sexual conversations are, ehm, well you don’t witness so many but you use your, maybe your skills from say breaking bad news in that context.....and so I’d use those same sort of skills I’ve learned for that in talking about sexual problems. I don’t think I’ve ever watched anyone else talk about it.”

[HCP1: Female specialist registrar]

Some doctors felt they were confident in being able to address the biomedical aspects of sexual morbidity such as menopause management, and advice relating to the use of vaginal creams and lubricants.

“Plus you have lots of ideas of what you can do sort of, er, so for example if the woman’s complaining of dyspareunia, you know, or vaginal dryness or something like that, you know, that there are for example creams that you can prescribe them and give them and at the end of the day a patient’s presenting to you with a symptom you potentially have an idea of what you can do for them which will benefit them.”

[HCP14: Male specialist registrar]

Although other health care practitioners recognised that this type of knowledge may be more appropriate in the management of male sexual dysfunction where there were more specific biomedical interventions to offer, as opposed to female sexual dysfunction where this was not yet the case.

“HCP10: I think Viagra has a lot to do with it, I really do. And I think it’s out there, isn’t it? It is out there, you see Pele advertising.

Researcher: Yes, that’s right, and Stirling Moss.
HCP10: I think men, because it's a physical thing, seem able to...and also I think the surgeons address it when they talk about surgery with them. I mean when I sat in on those consultations they [surgeons] all addressed it [erectile dysfunction] with them [male patients].

[HCP10: Female clinical nurse specialist in gastrointestinal cancer]

While nursing staff appeared to have been able to access a greater number of study days or short courses that contained material about treatment related sexual morbidity, the majority of health care practitioners felt that training provision in this aspect of pelvic radiotherapy practice and late effects management was inadequate and in need of improvement.

“Well, the other thing obviously would be, and again it's a tough one, would be better education of doctors in training, especially those giving any form of pelvic treatment, but I suppose pelvic radiotherapy, because it can be so disastrous from a sexual front and others, ehm, there just isn't the emphasis in training on such issues, there really isn't. And that goes for all toxicities but in particular sexual. You know, certainly my own training was vastly deficient in that regard.”

[HCP03: Male clinical research fellow]

9.5 Category Summary

The findings explored in this chapter speak of the challenges inherent to the discussion of treatment related female sexual difficulties within the context of conventional oncology follow up clinics.

Unsurprisingly the discussion of sexual concerns in this context is viewed by the majority of health professionals and patients as problematic. Factors that had a negative impact on the exploration of women or couple's sexual concerns emanate from the culture and environment of the oncology clinic, the health professional–patient relationship and the nature of cancer as a life threatening condition. Health professionals, women and their partners concurred that the dominant clinic agenda remains the detection of disease recurrence and the management of acute treatment toxicity. Within this illness context it may be difficult to accord treatment related sexual difficulties sufficient priority for it to become an integrated topic of pelvic radiotherapy post-treatment review, particularly in the initial period of the woman's recovery.
As women began to resume the broader range of lifestyle activities associated with recovery from a serious illness they became more likely to enquire about persistent changes in their bodies and this could include alterations in their sexual well-being. It was at this point, when sexual recovery became more relevant to the woman and her partner, that the practitioner's ability to create rapport and to promote effective communication became the most important factor in determining whether or not sexual concerns could be safely and sensitively explored in the clinic.

Analysis of the interview transcripts appears to suggest that health professionals find the discussion of sexual issues inherently difficult and adopt a variety of communication strategies to try to reduce embarrassment for both themselves and the women they are trying to assist. Predictably these strategies supported the limited discussion of functional or biomedical aspects of sexual morbidity through their linkage with treatment induced vaginal toxicity, ovarian failure, infertility or the use of vaginal dilators and excluded the emotional or relationship aspects of female sexuality more commonly encountered in psychosexual practice.

Women and their partners were aware of the potential for embarrassment but expressed a preference for health professionals to take a proactive stance in providing more detailed information about treatment related female sexual difficulties in order to bring patient information on this topic in line with the perceived emphasis on bowel and bladder late effects within the clinic. However, because health professionals lacked knowledge about the specific difficulties women encounter or how best they should be clinically managed they remained reluctant to raise the topic within consultations.

Factors that reduced the difficulty experienced in addressing sexual concerns largely related to the creation of good rapport in patient-professional communication. For some practitioners and a minority of women this included having same gender consultations and better continuity of health care personnel within the clinic so that sensitive patient information did not have to be repeated each time the woman / couple attended the clinic.

Health practitioners felt they would be more likely to address women's sexual concerns in the follow up clinic if they had clearer referral pathways, improved awareness of specialist resources they could access in their locality and greater knowledge of the specific sexual difficulties experienced by women after pelvic radiotherapy together with clinical management approaches. The majority of health professionals interviewed felt ill-
prepared to offer an appropriate response to the sexual concerns expressed by women in their care and sought to improve this inadequacy through the individual and organisational strategies and developments discussed in the next chapter of this thesis.
Chapter 10: Assessing the Sexual Consequences of Cancer Therapy in Practice

This chapter addresses the specific changes that health care practitioners, women and their partners believe may be necessary if improvements in the clinical assessment of female sexual difficulties associated with radical radiotherapy are to be achieved. These changes address perceived deficits both at the level of individual practice (knowledge and communication skills) and those emanating from systemic or organisational limitations such as a lack of specialist patient education materials, the absence of appropriate referral pathways and a lack of specialist services within or beyond routine oncology follow-up.

Figure 10.1: Data categories and sub-categories: Assessing the Sexual Consequences of Cancer Therapy in Practice

As can be seen from figure 10.1, initial data coding led to the emergence of five separate sub-categories. However, closer scrutiny of the data sub-category A question of resources revealed that transcript data coded under this heading overlapped with the preceding two sub-categories namely Finding the right person and Developing better strategies. Thus final data coding led to the deletion of A question of resources and
data were appropriately coded under the existing four sub-categories that structure this final findings chapter.

10.1 Engaging the couple

Participants expressed a range of views regarding the benefits and challenges associated with greater inclusion of women’s intimate partners in discussions about treatment related sexual difficulties. Overall, women expressed a more positive view about having their partners with them during such discussions (n=8) compared to only three health professionals who were positive about the contribution that increased partner involvement could make.

"Researcher: And how would you have liked that [sexual morbidity] information, would you have liked it verbally, would you have liked written information or websites that you could have visited?
PT16: I would have liked it verbally and I think verbally to both of us.
Researcher: So you’d like your partner involved?
PT16: Yes, yes.
Researcher: And do you think he would have wanted to have been more involved in understanding what was happening to you and thus the effect it had on you both?
PT16: Oh yes, yes, yes……But on the other hand, you know, he did a lot of research and knew more about it [her illness and treatment] in a way than I did, you know, so maybe he knew [about sexual implications], but I wasn’t particularly aware of that...."
[PT16: 56 year old woman 24 months post surgery / radiotherapy for endometrial cancer]

"I think it would be good if you have it [discussion about sexual concerns] afterwards [post-treatment] then you can sit down with the doctor and your partner and then if you’ve got any concerns then it can be, you know, gone through there and then.
Researcher: That’s an interesting point, do you think we should involve partners a bit more, because we don’t always.
PT20: I think you should because it’s a bit, you know, to a lot of people their sex life is a big thing in their life and it could be a matter of whether they are going to, you know, start looking somewhere else. But in my situation my boyfriend’s been along to all my appointments and often he has taken in information that I never did……and we talk about everything so we are quite lucky there, but I think it would be a good idea to do after, to do it after the treatment.”
[PT20: 33 year old woman 22 months post chemo-radiotherapy for cervical cancer]
"I think if you've got a married couple and they're youngish, I think the men should be made aware by another party because that close relationship can be very, ehm, I would say like a mine field. Because a woman will be feeling inadequate, she may be feeling angry, hurt, upset, unloved, scared....as I say, I have been very lucky, very, very lucky. I mean, you know, I should think it could ruin some marriages and that's not good, it's not fair really because.....I think a lot more importance should be given to it [sexual adjustment]...."
[PT23: 58 year old woman 29 months post chemo-radiotherapy for anal cancer]

The perceived benefits of involving a woman's partner in such discussions ranged from increased partner understanding of specific changes anticipated as a result of pelvic radiotherapy, to health professionals becoming more aware of the couple's ability to cope with the extra relationship demands often associated with cancer treatment.

"Researcher: Have you had many occasions when you've talked about it [sexual morbidity] with a partner present and what do you think about involving partners?  
HCP17: I think they should know about it because it might not be something that's been brought up at all and they are not going to be aware, until they can actually see where, it helps to show them a plan as well because with a male approach to things they want to see what's happening so if you, if you can be a bit more explicit about this and why it is happening and you can talk about the effects on a young woman who is going to have their ovaries damaged, so their hormones aren't going to be there, so they are going to get menopausal, so they are going to be miserable anyway, they're going to be sore, they're going to be sick and they're going to have diarrhoea, cystitis, they might not feel very romantic."  
[HCP17: Female Therapy Radiographer]  

"Okay there are some things we can help with, you know, and often if the partner and woman were together I find it easier......Because (a) you can establish what they both want, because when you've one person wanting one thing and another person something else it's very hard because you don't know where you are. I mean I know, fair enough. If a woman says 'it's not an issue for me' and she's doing things because the partner wants it, it's very difficult. They need help for the two of them because you can't help just the one person I think. So I found it was easier to talk to both of them, both of them felt they wanted help or at least if the woman, you know, started talking and then she went to RELATE, they both found that a big help, rather than I think it being one person's fault. Because it isn't in a relationship."  
[HCP10: Female clinical nurse specialist in colorectal cancer]  

Three women expressed mixed opinions regarding the presence of partners during discussion of sexual concerns. For these women this ambivalence appeared to emanate from either personal knowledge of their partner where, for example, he may be embarrassed by such discussions, or the woman was uncertain about how the differing needs of both parties would be managed sensitively within couple discussions.
"Researcher: Do you think partners should be involved in some of the discussions that we've been talking about?
PT14: If they are feeling comfortable about it, that's the only thing I can say. I mean if my husband was sitting here he'd be terribly embarrassed."
[PT14: 63 year old woman 4 months post surgery/radiotherapy for endometrial cancer]

"Researcher: Do you think it would be helpful to have partners more involved in asking questions or having a discussion around how it might affect one's sex life after treatment?
PT22: Well I suppose for some couples, you see, it could almost break them up I think, do you know?.......Yeh, I think it would be nice.......I think initially........How it would be nice would be maybe for the lady first of all and then separately for the man and then come together. You know, I think that would be.....because like sometimes he might want to get off his chest that, well she's gone really cold and not want to hurt her with that. Or, ehm, I don't know but he, his side of it really. And obviously the lady can put her side to it and then if they have this burning need to get it right it will be nice to have that followed through, really."
[PT22: 51 year old woman 31 months post surgery / radiotherapy for cervical cancer]

This particular woman [PT22] had been unable to resume regular intercourse with her husband due to persistent dyspareunia and beliefs she held about reactivating her cancer through sexual activity. Her interview contained a number of references to the guilt she felt about unmet sexual needs she perceived her husband had and she expressed regret at having nobody with whom she could discuss sexual concerns until her research interview some 31 months post-treatment. This may explain why she outlined how best to engage both partners within the couple in order to fully appreciate their individual and shared need for information and support.

Two health professionals (HCP03 and HCP17) also expressed mixed views about the contribution of partners to discussions about treatment related sexual difficulties within the clinic. Although practitioners were generally supportive of the principle of greater partner involvement, they also expressed some hesitation based on negative personal experiences of the challenge inherent in managing the communication dynamics of sensitive three way discussions.

"But what I used to try and do, especially when I was doing a lot of prostate work, was never be inhibited by a partner being there. And often, in fact, it's the partner that talks about it [sex] more than the patient. So I am used to the partner taking full
part, if not often taking too much part in the conversation, you know. They are, I think they often think they are being helpful by saying lots when in fact sometimes you, while you want them to speak, you want the patient to be feeding back to you more......I'd probably prefer them to be there overall if the patient's cool with it...."

[HCP03: Male clinical research fellow]

Four health professionals and one woman (PT06) expressed negative views about having partners present during discussions about sexual consequences of cancer treatment. For PT06 [72 year old woman 12 months post surgery / radiotherapy for endometrial cancer] it was simply that she preferred to "deal with it myself." This lady and her husband were still sexually active and she had made an uneventful sexual recovery post treatment.

Some health professional's reluctance was either related to a belief that the woman's disclosure of sexual concerns would be adversely affected by her partner's presence or disquiet about being able to manage discussions about sexual concerns with a male partner present.

"Researcher: If, for example, a woman is in a consultation and she has her partner with her does that make it easier or more difficult?
HCP08: No, I think it makes it more difficult. For me it makes it more difficult.
Researcher: So what's in your mind when you've got that third party sitting there, is it an issue of confidentiality or what is inhibiting?
HCP08: Well sometimes I think that it, it's inhibiting in that not.....I don't think the patient always wants to talk in front of their husband or partner, ehm, and I think that by and large women can actually have very, very close conversations about sex and sexual dysfunction whereas I think with men it all sort of, it brings in kind of a completely different dimension. And I think too that women will tend not, if the male partner there they won't talk about their needs, they'll be thinking about what impact it's going to have on him, how embarrassed he is going to be, how humiliated he's going to be, what's going on rather than sort of opening up about themselves..."

[HCP08: Female consultant clinical oncologist]

"HCP12: And I think if they're there with their partner it's even more difficult. Very, very difficult.
Researcher: When you've got a couple in the room does that change the dynamic of the conversation you might have if the woman was on her own?
HCP12: Ehmm, yes, it would. I personally would be, the word intimidated is there, and I don't know why I would, but I think I would. I really would. Because again it's very difficult to, you want to be focussing on the patient, whereas the spouse might take over the conversation and then they might start bringing into the conversation their concerns, or something that's occurring at the moment......and I am not a trained sexual therapist so I think again it's finding that boundary and I think as long as you can get across to the patient where you fit in with all this and how far you can go......but like you said earlier, it's a very difficult area to discuss."

[HCP12: Female clinical nurse specialist in colorectal cancer]
Of the five male partners who were interviewed, three had felt excluded (PTNRs 01, 03, and 05) from medical consultations that tended to focus solely on the treatment experiences of the woman as opposed to exploring the impact treatment may have been having on the general or sexual relationship of the couple.

“I think it needs to be inclusive of, you know, both people. I would imagine that the outcome is clearly of the traditional approach to medicine, if something’s wrong with you, you say we’re going to fix you! The fact that in this particular instance, in many instances, but in this particular one there is a severe intimate knock-on effect. It’s ‘don’t forget to tell your husband if he’s not there, or have a discussion’ but it’s still focused on the individual [with cancer]. And it needs to focus on the couple and potentially offer some advice through experience as to how to overcome these difficulties if they arise, should they arise, who do you come and talk to? And maybe individually counsel the partner who’s not having the treatment but is affected by the treatment. . . . I would have liked it if it had been specifically addressed to me. . . . And these are the things we can do to help you in your relationship!” [PTNR01: 41-50 year old husband of PT09, 50 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

“I don’t know, it’s just a trait of mine that in fact there would have been rather, I suspect, a rather selfish attitude that in fact the focus is all on the treated partner, that there’s a sense of . . . there’s a risk that the partner feels left out, not considered. My own experience I didn’t feel that but I suspect if I’d been in my mid-thirties I might, because I’m just thinking of situations when the focus, quite rightly, was on the drama elsewhere. So yeh, to build in that fact, just to make sure the partner feels fully engaged and part of the consultation process. I think we were fortunate in the clinicians we dealt with so . . . well it is important because unless the partner feels involved to a certain extent, he can’t focus as well as he should on providing the level of support needed.” [PTNR05: >60 year old partner of PT21, 54 year old woman 18 months post chemo-radiotherapy for cervical cancer]

Despite what appeared to be an initial satisfactory sexual adjustment for this couple, PTNR01 had developed erectile difficulties approximately 12 months following completion of his wife’s (PT09) treatment and at the time of his interview he was awaiting a GP referral to evaluate his sexual difficulties. This may be why this gentleman felt particularly strongly that health professionals should actively enquire about the partner’s well-being and personal circumstances when considering sources of support for the woman who is being treated for cancer.

One of the partners (PTNR04) had felt adequately involved in discussions about sexual difficulties through attending all of his wife’s follow up appointments. This couple (PT16 / PTNR04) had initiated discussions about their experience of dyspareunia with both surgical and clinical oncology consultants and received a response that engaged them
both equally. Finally, PTNR02 was neutral about couple focussed discussions related to sexual concerns as he felt he would have asked a direct question about sexual recovery as needed.

10.2 Finding the Right Time

Health professionals expressed diverse views about the most appropriate time(s) within the patient's treatment journey to raise issues related to sexual morbidity associated with pelvic radiotherapy. This apparent lack of consensus regarding the optimal time to discuss this topic suggests that sexual morbidity may not be viewed in the same way as other late effects such as those affecting function of the bowel, bladder or gonads. This lack of consensus was manifest through the omission of sexual consequences of treatment when addressing treatment toxicity as part of consent processes (see Table 6.2). At treatment site A, structured consent forms listed a range of both immediate and delayed treatment effects that were considered important to discuss with women before pelvic radiotherapy could begin. The development of vaginal stenosis was not specifically listed on the consent forms despite being a relatively common vaginal toxicity with specific sexual implications. In contrast the rare treatment effect of fistula formation was included, perhaps because it was considered by health professionals a more serious treatment complication.

This omission of vaginal stenosis from all consent forms and failure to include vaginal toxicity in the consent forms for bladder, anal or rectal radiotherapy meant that the decision to discuss these treatment effects would be left to the discretion and recall of individual health professionals.

Some doctors felt that sexual difficulties emanating from vaginal changes should be discussed at the time of obtaining consent for radiotherapy while others considered this inappropriate because of the volume of information women had to understand at a time when they were still adjusting to the wider implications of a cancer diagnosis and embarking on intensive treatment.

"Researcher: And aside from the follow up period are there any other points within the patient’s cancer journey that you would tend to make an assessment of sexual well-being?
HCP18: I would hope that the nurse specialist would have asked those questions [about sexual concerns] at the time of consent for radiotherapy and, seeing the
patient for the first time in the clinic, which is often post-op......if it's an adjuvant
treatment. And quite often the clinical nurse specialist does have knowledge about
sexual function and sexual activity etc.”
[HCP18: Female consultant clinical oncologist]

“No, I think it would be very uncommon to talk about difficulty with intercourse. I
would talk specifically about side effects on the vagina but at the informed consent
stage that would not be discussed usually. I mean if the patient is worried about it,
we would discuss it, but I don't bring it up at that stage.”
[HCP20: Female consultant clinical oncologist]

“You don't tend to discuss it [sexual concerns] because there's a lot of other things
you are discussing and at the time when you consent people they've usually had
surgery often and when they come to see you there are so many things you have
to cover that actually that doesn't get covered at all.”
[HCP06: Female specialist registrar]

The provision of patient information at different points in the patient's treatment
trajectory is discussed in detail within chapter six. Health professionals acknowledged that
prior to and during treatment, and in the initial weeks / months after treatment, the focus of
patient assessment was a combination of disease surveillance and acute treatment
toxicity. Hence, sexual morbidity may not have been discussed in the early stages of
treatment and follow-up because it was considered a treatment late effect and unlike
toxicity affecting the bowel and bladder does not have an acute manifestation unless the
women has remained sexually active during radiotherapy treatment, which is unusual.

A number of health professionals expressed difficulty in knowing when best to
discuss sexual issues with women during follow up because they were often weighing up
the changing priorities that both they and the women had to consider in the context of
acute treatment side effects, fear of recurrent disease or the delivery of bad news about
treatment response.

“....I think for a lot of them they are concentrating on their treatment so they don't
actually think about the future, and for some of them, for a few people they have
actually said where they've got their cancer they feel that it's almost like, it’s put
them off having sexual intercourse. It's the thought that that's right near their
cancer. I feel that at the beginning [start of treatment] it's just a little bit too intrusive for
some people and they will tell me later, I just get that feeling they will tell me later.”
[HCP07: Female Radiotherapy Department Nurse]

“....because if their scan result is not good then you are not going to bring it [sexual
concerns] up.”
[HCP06: Female specialist registrar]
Women who were being treated for low rectal tumours posed a particular challenge arising from their specific schedule of multi-modal treatment. These women were asked to commence the use of vaginal dilators approximately four to six weeks after their chemo-radiotherapy but this was also the same time that these women transferred to a surgical unit, sometimes within a separate Trust, to have their rectal tumour resected.

"The dilators, we would say start using them about four weeks after treatment finishes or when they are comfortable. It used to be six weeks but for those that are having treatment for GI cancer and then they are going to have surgery afterwards, quite often that surgery is at six weeks so if they haven't started using them and then they are very uncomfortable after surgery it's going to be a long while before they start using them, so that's why we say four weeks now."

[HCP07: Female radiotherapy department nurse]

No individual practitioner or team appeared to take overall responsibility for ensuring that these women were supported in being able to start vaginal dilation at the optimal time after surgery.

"We never see them [women having surgery for lower rectal cancer] and I think it would be quite possible....I'm just wondering whether they go back to the hospital they were referred from in the beginning for follow up? They may be followed up, I suppose, sometimes here [cancer centre] as far as the radiotherapy is concerned but it may be that they go back to their original hospital."

[HCP07]

This lack of care pathway coordination also meant that surgical and clinical oncology teams operated on a series of assumptions about whose responsibility it was to ensure that the sexual implications of both surgery and radiotherapy treatment were addressed with the woman / couple.

".....when they come back in a month's time does anybody address [sexual concerns], because their next step is surgery, it's not something they want to address.....They are not going to, they are just wanting to get over going through the surgery. It's really afterwards when they have had their surgery and come back when those issues become, you are not addressing it. I really don't think we are addressing it at all. I mean I say to the doctors, you know, did you ask them, did they get advice, have they got any issues?' 'Oh but they are going back to the surgeons next week', so they assume the surgical team will discuss it."

[HCP10: Female clinical nurse specialist in colorectal cancer]
A consequence of this confusion was that in the absence of guidance from their treatment teams or systematic evaluation of dilator compliance by practitioners, women were often left wondering when it was safe to commence dilator use or to resume sexual contact.

"Researcher: One of the things we have difficulty is given everything else you are told about and how much you are going through, emotionally, when is the best time for us to broach the subject [sexual concerns] with you? Had you any thoughts about it?

PT07: I think probably a couple of months after the operation would be better. Eh, because when I was in hospital I asked [surgical nurse] about doing the dilator and she wasn't quite sure, eh, and I had to phone....I phoned up the [cancer centre] to ask them and the nurse [HCP07, radiotherapy department nurse] said 'Oh do it as soon as you can because you need to keep it open' and all the rest of it. So then we've started it [dilator use] but I didn't, I must admit, I didn't start it for about six months after the operation."

[PT07: 63 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

As has been mentioned previously, this lady developed severe stenosis following treatment that included resection of her posterior vaginal wall and had been unable to use vaginal dilators satisfactorily or resume penetrative intercourse by 12 months post-treatment.

Ten health care professionals expressed a personal opinion about what they considered to be the most appropriate time to discuss sexual concerns with women. Five health professionals felt these discussions should take place at the time of consent or during radiotherapy, while the remaining five health professionals preferred a time post-radiotherapy ranging from four to six weeks (HCP15: outpatient staff nurse) up to six months (HCP12: clinical nurse specialist in colorectal cancer). Therapy radiographers and staff nurses tended to suggest times related to their own period of contact with patients, at the start, during or immediately following completion of radiotherapy.

".....but when they are coming like say one month post [treatment] you can discuss then because somehow they relax, they've done it, they've finished and they didn't die because of that. They are more absorbent like to whatever you tell them so you can discuss then about the sexual function, about the dilator, about the family life and what they expect and what to think about the prognosis. People are coming back and they warm up to you and you find the time that you can actually say anything you want to say, so you just have to wait for the time."

[HCP15: Female outpatient staff nurse]
Doctors and clinical nurse specialists also proposed times commensurate with their access to patients, namely at treatment consent or during treatment follow-up.

“…..you know you’ve got a window of opportunity haven’t you? Three to six months afterwards whereby people are starting to get adhesions and so forth, things that can become a problem. And you just sort of wonder whether in a really good practice what you would do is you would routinely [see women] at three months following treatment. This isn’t a recurrence clinic, or whatever, this is an additional separate visit to a clinic with, er, maybe not doctors.”

[HCP05: Male specialist registrar]

“Especially at the six weeks [follow-up], because I think sometimes, you know, it’s probably not relevant to talk about sexual intercourse at that time. And even at three months it’s sometimes far too early. But I try to lead in with the idea of whether or not they are actually using their dilators and then might ask them if it’s made sexual intercourse….have they resumed sexual intercourse and I usually ask them a direct question. And I probably think that, yes, I think that it’s probably the sort of minor part of my discussion at that time.”

[HCP19: Female consultant clinical oncologist]

The challenges associated with finding the right time to speak about treatment related sexual difficulties was also felt acutely by the women going through treatment. Many women viewed their treatment period as a particularly demanding time where information overload could be a problem and getting through radiotherapy to achieve disease remission was their only priority.

“So for anyone to talk about it [sex] then its phsewwt, forget it! [ makes a gesture of something going completely over her head]. And then you’re downstairs [in radiotherapy department] with those people, you know, they’re fine but it’s very much, you’re just trying to fucking get to the next day, or whatever. I like the idea, you know, I’ve heard people talking about a gynaec nurse…. I suppose sometime afterwards, maybe after you’ve had your check up where they say you’re in the all clear. But it would have to be at the right time……You have to know you’re gonna live before you’ve got any interest whatsoever in [sex]….so there’s no point beginning when, you know…..”

[PT01: 45 year old woman 21 months post chemo-radiotherapy for cervical cancer]

Other women wanted information about sexual consequences at the start of their radiotherapy alongside the discussion of other treatment induced effects.

“So I would think that fairly early on, when you are going to have to, you know…..we’re going to give you a treatment, this is what, ehm, is recommended as the course of treatments you are to have. That is the point where you need to be able to sit down with a nurse, like [gynaecology sister] to go through everything, which will also cover the sexual side of it. I think everything about the whole thing is
advance; it's preparation in advance all the way along. But I would have liked it at some point when I was starting radiotherapy, at some point then, I would have liked something so that having all this massive information on bowel and mostly on bowel, with quite a bit on bladder, but nothing at all on genitals. I would have liked something then. And then probably, you know, another follow-up session.”

[PT03: 55 year old woman 8 months post surgery / radiotherapy for endometrial cancer]

A number of women felt it was not always an appropriate time to discuss sexual implications of treatment while they coped with recovery from surgery or with the unpleasant pelvic side effects of chemo-radiotherapy.

“.....the fact that the diagnosis was a shock, then things happen very quickly, then you are in hospital, then this, this and this and suddenly you sit back and think 'My God' you know, 'It's a lot' so all those times no, I don't think you could take that [knowledge of sexual impact] as well. You think it would be the last thing you would think because you were so...your skin was so angry and so uncomfortable it's the last thing you want on your mind. So maybe, I don't know, a couple of months down the line after treatment is probably quite a good time. But as I say it didn't even occur to me, and the only reason the nurse mentioned it to me was because I was having such a rough time trying to get the skin to heal and she was giving me all this advice and stuff, that it even came to light then, so......but yeh, I think it takes time to get over this pelvic stuff so I should think a good couple of months afterwards is probably a good time.”

[PT08: 58 year old woman 6 months post chemo-radiotherapy for anal cancer]

Here too there was evidence that information about sexual morbidity was viewed differently by women from the information about skin, bowel and bladder side effects that was needed because of its immediate relevance to the women's daily comfort and recovery.

Interview transcript analysis revealed considerable diversity of opinion about women's preferred timing of discussions about the sexual consequences of treatment and this creates a challenge for individualised care delivery. Some women expressed a personal preference for advance information as a coping strategy, while for others the timing and level of detail desired was more dependent on individual side effect burden, rate of recovery and the relative importance women placed on sexual adaptation post-treatment.

“So I think once you have had your check up like anything, once you know and you have had, as far as you can, an all clear, I think you are happier to think, well then, it's all healed up down there, it's alright. You know, because I think from the physical side you need to know that before the mental bit comes in.”

[PT06: 72 year old woman 12 months post surgery / radiotherapy for endometrial cancer]
“Researcher: Do you think if your consultant were to have asked you questions about your sexual recovery as you were going through follow-up you would have been insulted or upset by those sorts of questions?
PT11: No, I think I would have been more amazed at how can anybody be possibly have been thinking about my sex life when I'm finding it hard to walk up the stairs.”
[PT11: 59 year old woman 12 months post surgery / chemo-radiotherapy for cervical cancer]

Of the seventeen women who expressed a preference for the timing of discussions about sexual impact of treatment, nine felt discussion of sexual concerns should take place after completion of pelvic radiotherapy and they had begun to recover from their illness and acute treatment side effects.

“With me, because I finished, it’s been a year since I finished my treatment I think I feel it’s the right time. But had you asked me when I was having my treatment I think that was a secondary concern. My main focus was on getting better and sex was something I wouldn’t even dream of at that stage, so maybe asking after the treatment.” [PT13: 32 year old woman 16 months post surgery / chemo-radiotherapy for cervical cancer]

Eight women felt that raising sexual concerns should occur at multiple points during the woman’s treatment trajectory in order to monitor for the development of sexual difficulties over time.

“I think it’s good to, even when you’re going through treatment although you don’t want to hear it, it’s good to know that somebody is asking you these questions. Although they’re not expecting you to be doing any of those things, you know, you kind of do have that repetitiveness of being told at the beginning, the middle and the end…..”
[PT05: 36 year old woman 12 months post surgery / chemo-radiotherapy for cervical cancer]

Three women felt they could not state a specific time preference as their need for information and support was related to their personal circumstances, coping strategies and open to fluctuation.

“Researcher: One of the difficulties we have as health professionals is knowing when is the right time to make an approach; when is the right time to ask questions about sexual recovery? I mean what advice would you offer us from that point of view?
PT12: ...I mean I guess everybody’s so different in their attitudes, how they deal with it, when it’s an issue, when it isn’t. I guess from a service point of view that is
an impossible thing for a service to meet, really, and to judge accurately. I guess it's a bit for me I think it would have been OK. Like it was raised early on with [name of CNS], in my conversations with her. And I think, for me, I would have liked someone just to have been checking with me at least on a monthly basis, or every six weeks and just raising it again. And if, you know, then it's my choice as a patient if I want to take that further but just to know that it's OK to do that, almost like you have been given permission.”

[PT12: 42 year old woman 14 months post chemo-radiotherapy for cervical cancer]

The diversity of opinion expressed in both health professional and women's interviews regarding the most appropriate timing of discussions about treatment induced sexual morbidity reveals a challenge for service provision. How can the timing of patient information and support be systematic in order to reduce care omissions, while at the same time remaining responsive and sensitive to individual patient characteristics? This apparent tension in the development of an optimal approach to the delivery of information and support regarding women's sexual difficulties is discussed in more detail within section 11.4.

10.3 Finding the Right Person

Study participants were asked who they felt was the most appropriate person to address sexual concerns with women and their partners. Women appeared to base their choice of suitable personnel on their knowledge of the practitioners they had encountered and with whom they had been able to form rapport and trust.

“Well because I had to see the nurse so often I got to know them. It's who you're more familiar with, that you feel comfortable about it, although there are three or four of them you didn't see all of them all of the time but I think it's who you are used to.....If I hadn't burned so badly I don't suppose I would even have seen them but because I did, they are quite good people to talk to. They are very understanding when it came to the burns and all the rest of it and I could feel that I could say anything to them and felt comfortable about it because I've got used to them, it's somebody familiar and that's quite good.”

[PT08: 58 year old woman 6 months post chemo-radiotherapy for anal cancer]

In the main, patients and their partners stated a preference for continuity of personnel and for those addressing their sexual concerns to be members of their existing treatment team(s) as opposed to external specialist counsellors or services.
"Researcher: You'd rather have that sort of support from people that are clearly linked in with your treatment centre, or people you have met already?

PT24: Yes, yes. I think if it was still associated with the [cancer centre] I would have done it [attended sexual counselling] but if I'd had to go to an outside agency I wouldn't." [PT24: 54 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

"No I think the smaller the team the better. But obviously within the thing [treatment team] because if it goes too far you're getting too remote and they've, you know, begun to get a relationship with that team and you see a different person, but they're all within the small team and that's where it should stay." [PTNR02: >60 year old husband of PT10, 68 year old woman 24 months post radiotherapy / surgery for rectal cancer]

Where women felt specific members of their treatment team were not appropriate to act in this capacity this was usually because either they had not formed a comfortable relationship with that practitioner or, as has been discussed previously, the women did not feel sexual issues were a medical problem to take to their specialist or consultant for discussion.

"That's probably unfair to say but I suppose it really does depend on the consultant. I know that's his speciality but if I think about my gynaecological consultant who did the hysterectomy he wasn't at all dismissive, he is just wonderful. You could talk to him, he's great, he has a wonderful attitude to people......I'd have felt I could certainly go back to him and....now I'm not saying that I couldn't with [consultant clinical oncologist], it's people's reactions to each other and I probably wouldn't go back to him, I would go to my GP and say I'd like to talk...." [PT19: 62 year old woman 17 months post surgery / radiotherapy for endometrial cancer]

Only a minority of women appeared to consider the specific skill set or knowledge base of the staff they suggested to offer support and information regarding sexual recovery post-treatment.

"PT11: I don't think it would have occurred to me to approach the treatment team, to be honest. No, they got me better when I was ill sort of thing and they are trying to keep me better so I wouldn't have thought that was their sphere of expertise really. I suppose we [couple] would have talked about it and just hammered it out between ourselves.

Researcher: Would you go to your GP? Would that be a source of support or help?

PT11: I suppose if it became very important in that one or other of us was desperate to reactivate a sexual life then yeh, I could talk to my GP, actually she's very good, but having said that what would she do? Probably send us off to counselling or something!" [PT11: 59 year old woman 12 months post surgery / chemo-radiotherapy for cervical cancer]
Some women expressed a preference for a practitioner who could offer them specific practical advice and hence this meant they were more likely to suggest a nurse in this role.

“I think in fact it's more useful particularly with a nurse or someone who has some, not necessarily the consultant, I think somebody who's on the practical level and sees these and probably knows, you know, so much more about the sorts of things, I mean sometimes you think ‘Oh God, I couldn't ask that and be so stupid!’ You know, but I wouldn't like to ask, I'd probably think, I'd think ‘Oh [consultant name] will probably think I'm mad!' You know, and I suppose because it's a man as well. Not that that's ever been an issue really, but thinking about it perhaps it would be easier to talk to a woman who's, you know, obviously built in the same way. So yeh, I think that is quite a good idea and possibly reasonably soon after [treatment]...”

[PT21: 54 year old woman 18 months post chemo-radiotherapy for cervical cancer]

As discussed in chapter nine, some women reiterated their preference for a female practitioner as someone who was felt to be easier to talk to about this sensitive topic and to be more likely to empathise with their sexual concerns.

Health professionals tended to liaise with someone from their existing clinical team or with staff accessible within the cancer centre. None of the medical staff interviewed had specific knowledge of or had established professional links with outside agencies or personnel specialising in sexual health or counselling.

“Well I would involve one of our CNSs because they are all terrific and know the patients terribly well and I think would have a very easy and generally have an easy rapport with patients so I would involve them in the discussions. But it would generally be, I've never sent anybody to anybody with a particular interest in sexual dysfunction. I don't know if there is anybody in the locality but I have sent them to probably a gynaecologist either outside or particularly within the [cancer centre]. The ones that work on the gynae unit here who see a lot of patients post radiation for the gynae oncology service and, you know, have discussions with them, well that's why they're asked to see the patients.”

[HCP08: Female consultant clinical oncologist]

The majority of doctors viewed the clinical nurse specialist as their first point of referral if they elicited a sexual difficulty or if a woman needed further information about medically induced menopause or infertility.

“I'd probably phone up [first names of two gynae-oncology clinical nurse specialist]. I'd phone them up and go ‘I've got this problem and who, what's the best way to go
about it?' Because they probably know best the services to access because I'm not really aware about services at this hospital and also because the patients come from far and wide. And then, then what usually happens they will pick it up and they'll say, 'That's fine I'll give them a call at home, I know who they can see'. So I tend to be guided by them and if they weren't there I'd be quite stuck."

[HCP06: Female specialist registrar]

"Well I think I've been extremely lucky with my clinical nurse specialist in that she's tended to take patients on initially and then refer them on to a sexual counsellor where appropriate or if she's out of her depth or where she can't actually afford the time, so I've done it through that route really. I wouldn't tend to send them directly to a sexual counsellor."

[HCP18: Female consultant clinical oncologist]

Some doctors felt that clinical nurse specialists in colorectal cancer did not always have the necessary knowledge of radiotherapy and its impact to be able to offer women with radiation induced sexual morbidity the most appropriate information and support.

"HCP13: There is a surgical colorectal CNS but she's not so aware of radiotherapy issues and although she, I mean she's very good and you know she's very experienced in stoma care and all that, she's not really willing to take on more roles, I think...
Researcher: So she wouldn't be one you would automatically think of?
HCP13: No and I think she doesn't really understand enough about radiotherapy, when does toxicity set in, what are the problems and I think a radiographer trained, the radiography training would probably be helpful, or a nurse who you know would be interested in radiotherapy at least."

[HCP13: Female specialist registrar]

In these circumstances they would either attempt to have the woman seen by the gynaecology clinical nurse specialist or would opt to send the woman to a therapy radiographer or radiotherapy department nurse for assistance. Doctors did not always appear to discriminate between the levels of nursing staff or the disciplinary background of allied health professionals in selecting the most appropriate personnel for a woman to access.

Some health care professionals would refer the woman back to her GP, particularly for problems that were likely to occur some time after treatment completion or where it was anticipated the woman's difficulty would require medium or longer term intervention.

"If it's going to need somebody to give a bit of input and for there to be sustained input and follow it through, maybe half a dozen sessions with a counsellor, you know......or even back to their GP, somebody who they may know much better..."

[HCP05: Male specialist registrar]
Medical staff were also more likely to refer to other medical staff, namely gynaecologists where a specific problem such as dyspareunia or vaginal stenosis had been elicited.

"I would sort of work out if there was any reversible reason, but in essence for example, if they are having dyspareunia then a gynaecologist would be sort of the first port of call."

[HCP14: Male specialist registrar]

Radiotherapy nurses tended to operate within a relatively restricted sphere of influence and solely referred to either consultant colleague(s) or to the clinical nurse specialists in the cancer centre. This appeared to be because they only saw women during active treatment and focused mainly on the resolution of physical problems that could interfere with vaginal dilator use as opposed to addressing broader aspects of sexual recovery.

"I think if it's a physical problem using the dilators, we did have one lady who couldn't go back to, and I don't think ever has been able to go back to being sexually active and she used the dilators right but obviously there was a gynaec problem, there was something wrong physically, and I think I just refer them back to the team they were under.....so they can refer them to appropriate gynae people."

[HCP07: Female radiotherapy department nurse]

Clinical nurse specialists would tend to refer either to a CNS colleague, particularly colorectal nurse specialists to gynae-oncology nurse specialists within the same cancer centre or back to the woman's medical team if a specific physical problem was suspected. Three of the clinical nurse specialists had also made referrals to external specialist psychosexual counselling services in their locality.

"And as I say I've referred a couple of patients to RELATE because it was again much more psychosexual counselling, psychological, you know, rather than just....so yeh, I would check with [name of CNS in pelvic cancer] quite a bit just to find out where the resources are and then I refer on."

[HCP10: Female clinical nurse specialist in colorectal cancer]

"HCP04: Depends what the problem is. I mean it's either psychosexual counselling if I think it's a psychological problem, or particularly if it's a couple because I think that helps whatever, and sometimes clinical psychology but that doesn't tend to be couples.

Researcher: And the psychosexual service is outside the Trust presumably?

HCP04: It's outside the Trust and I'll either have to speak to the GP but generally, because of the nature of psychosexual counselling, because there's a service at [name of local health authority] you do tend to find that people do take patients because they're very small numbers, generally. And they are quite specific problems, you know, I think people are, well, they've always taken the people that I've sent...."

[HCP04: Female clinical nurse specialist in gynae-oncology]
"I wouldn't hesitate referring someone who I thought was having major problems and that's something I'm going to have to have to find out because, you know, I think you should refer on. I'm not a psychosexual counsellor, I'm not doing couple counselling and this sort of thing so, you know, I will refer on and I have referred on in the past."  [HCP09: Female clinical nurse specialist in gynae-oncology]

Again one of the clinical nurse specialists in colorectal cancer highlighted the greater difficulty she had in finding appropriate referral routes for women after rectal or anal cancer treatment compared to the men with treatment induced sexual problems.

"Now for men if it's erectile dysfunction you know you can send them to an andrology clinic and things like that. For women there are not so many people and I think I probably would go to my colleague the gynae cancer nurse specialist first for her advice to see if she's got any resources. If not I think they would have to be seen by the oncologist just for physical examination to see if there's anything obvious. I think you, I would first try and make sure there's nothing physical and if there isn't anything physical then you would probably have to look for someone in, not necessarily counselling but it's really trying to find the crux of the matter."

[HCP12: Female clinical nurse specialist in colorectal cancer]

At research site A there was a psychological medicine department but clinicians did not view this service as having the necessary expertise to address sexual concerns, despite using the service for other psychological difficulties.

"I have referred people to psychological medicine but not for sexual issues, no. Usually it tends to be problems dealing with the diagnosis or the treatment or afterwards so no, but then I suppose if I chatted to the CNSs they'd probably bring that up but I've never thought directly to do that as a first point of contact."

[HCP06: Female specialist registrar]

Site B had a comprehensive integrated counselling and complementary therapies service adjacent to the cancer centre outpatient area. This service was used to refer women with a diverse range of psychological concerns, including those with relationship difficulties, and practitioners at this cancer centre did refer women to psychological counsellors within this service where they felt onward referral would occur as appropriate.

"I think the [counselling and therapies centre]. I'm quite sure that they would have access to specialist help with relationship difficulties and which obviously is a spin off with lack of a sexual relationship, I would certainly refer them there......but as I say I would have confidence that the [counselling and therapies centre] would actually pass them on or indeed sit and listen to them."

[HCP16: Female therapy radiographer]
10.4 Developing Better Strategies

All clinicians, women and partners were asked if there were specific practice or service changes that they believed may improve the clinical assessment of female sexual difficulties associated with pelvic radiotherapy. Study participants agreed that the current approach to the assessment and subsequent management of female sexual difficulties after pelvic radiotherapy was inadequate and in need of substantial development, both at an individual practitioner and organisational level. A range of suggestions were made regarding improvements to the clinical assessment of female sexual difficulties in oncology follow-up. The most commonly proposed service change, suggested by six health professionals and eight women, was to establish a separate session or clinic within oncology follow-up services to solely address the sexual consequences of treatment. This was suggested because of the environmental constraints inherent to follow-up clinics and perceptions about the focus of medically-led consultations.

"Psychosexual issues, you know, and issues about body image and all that and I think you can't cover it in five minutes and that's one of the reasons why we sometimes don't address it because we know if we've only got five minutes, if we go down this route then you know all these other problems, you know we will run into problems and there are so many patients waiting. So I think it would be better perhaps to have this separate session, and I think you can separate it out. I mean it doesn't need to be together in one person. I don't think it needs to be a medically trained person, unless the medically trained person would have some more training into, you know, psychological issues, but that's always neglected in our training. It's only in the last two years I think we were kind of forced to have communication training."

[HCP13: Female specialist registrar]

"You know they've sat there for an hour, they've waited for you to come, they've waited to come in and I don't know, many of them are fed up by the time they get there [into follow-up consultation] and I don't know whether it's the right setting to be able to ask those sorts of issues. Especially also, you know, sitting in this tiny little room, people are coming in and out, you might be disturbed and it's just not conducive to talking about that sort of issue I don't think. Maybe that's just me passing the buck but I just, I certainly don't think I find it easy to....and sometimes you know you are sitting there and you are actually talking to them about...you are trying to talk to them about those [sexual] issues and, you know, the door opens and you have to stop......I just think it's not a great environment and maybe we need to be looking at the best way and maybe it's better, you know, what we've looked at here is having a clinic visit additional to the consultant visit or instead of, I think at maybe three months, maybe six months, where these things can be discussed in a much better environment."

[HCP19: Female consultant clinical oncologist]
"Researcher: Do you think we can accommodate the discussion around sexual concerns within the clinic or do you think we need to set up something separate to address that with a lady?

PT08: Ehm, I think separate. Separate. Because if it’s a one-to-one and somebody you are used to then it’s a bit easier than talking to who-knows-what in the room. So I think the separate issue is better.”

[PT08: 58 year old woman 6 months post chemo-radiotherapy for anal cancer]

“You definitely, most certainly need somebody that would follow through from your specialist I feel because one, it’s unfair on your specialist to have to get bogged down in these issues, they are not life threatening, and they’re caught up in your survival, you can survive without that [sex]. So I guess the nicest thing for me if I could have chosen would have been to have a kind of specialist in that area, for example, that I could have gone to, preferably female would have been nice, because you, you could probably open up a little bit more to those sorts of things. Yeh, I think you would definitely benefit from, you know, like having a second follow through maybe around your appointment or something like that, on the very day as part of like another clinic almost. Somebody who specialises in that side of it [sexual concerns] that you wouldn’t feel as though, because even now I don’t really feel I could actually go in to my specialist and say that because it’s not his forte, it’s not his field is it, really? He’s concerned in keeping me alive and what’s the best thing for me.”

[PT22: 51 year old woman 31 months post surgery / radiotherapy for cervical cancer]

Health professionals differed in opinion regarding the precise model of sexual morbidity follow-up they felt should be provided. Six opted for a new clinic to address treatment induced sexual morbidity in isolation, while four practitioners felt this new service should address all radiotherapy late effects, with sexual morbidity being only one aspect of this broader toxicity management remit.

“....and I think if you wanted to talk about the psychosexual side of it, it almost needs to be a separate session. But I don’t think we talk enough about psychosexual issues in general, we tend to assume that older ladies don’t have sex.”

[HCP02: Male consultant clinical oncologist]

“.....should there be, you know,. it’s maybe something that there needs to be people who specialise in that as a sort of, you do your medical part, you are looking for your disease recurrence, you are looking for the things that we can deal with, do something about would maybe be part of that. But there’s another part that is dealt with in an in-depth with somebody with the skills and I don’t think every doctor needs to have all of those skills maybe. That there’s a sort of, you know, separate....we don’t tend to have sort of late follow-up clinics that just look at the [radiotherapy] late effects.”

[HCP08: Female consultant clinical oncologist]
Four women stated a preference for this service to be led by a specialist nurse as opposed to medical staff.

"I can see that possibly because it touches on other issues of sexuality that the side effects or problems on the genitals perhaps isn't best dealt with by the doctors. Perhaps it isn't. Perhaps it is best dealt with by a nurse, but I think certainly with me, all it would have taken would have been one session.”

[PT03: 55 year old woman 8 months post surgery / radiotherapy for endometrial cancer]

“But in a way I think it is someone like yourself that would be more useful in dealing with women and after care and on the sexual side of it. I think it's easier for somebody to perhaps talk to on that score and as you come from a background of nursing you also have the information as well and you're more at the practical level than perhaps somebody who is a consultant. Although they, obviously, they are at a practical level because they are doing all the operations and things. But it's a woman and it's somebody who is seeing a wide variety of people in so many different situations and therefore you've probably come across all the questions that people might want to ask.”

[PT21: 54 year old woman 18 months post chemo-radiotherapy for cervical cancer]

Health professionals were aware that there were no clear referral pathways for the management of female sexual dysfunction either within or beyond the cancer centre and some spoke of the need to clarify levels of service provision offered within the cancer centre.

“Well I would like to know that we had a clear pathway down which to refer patients. And I would like that to be clear enough for people not to feel frightened initiating the process of asking patients about these things [sexual concerns]. Ehm, you know, so that if a junior went in and really couldn't deal with any of this on any level they could still start it and then know that they could take it as far as they are able......So I think in the long term that's something we need to develop a sort of pathway but it also goes along with having a proper pathway for asking about bowel toxicity and things like that.” [HCP02: Male consultant clinical oncologist]

“I personally think that the information giving about potential problems is the key to trying to reduce sexual problems afterwards. Or certainly to support some of the women who will never complain but whose life is unsatisfactory. And it is that group of women for simple, simple interventions. I think people who have serious problems are going to need specialist help and I don't really think there's anybody who has no problems, or they may find their own way round their problems but I think with a little bit of help they could have done that a bit quicker......the idea is that, you know, the volume of patients who actually need that specialist intervention could be lower if you pre-empt some of the issues.”

[HCP09: Female clinical nurse specialist in gynae-oncology]
Some health professionals suggested that the development of and adherence to care protocols or clinical management algorithms linked to referral pathways would be a way of standardising and streamlining what was currently an ad hoc and poorly coordinated approach to sexual morbidity assessment and management.

"Researcher: Have you any suggestions as to how assessment of late effects might be improved overall?
HCP03: My answer for this is almost, is a pretty boring answer, was the same as my answer for everything, is an algorithm, you know. Because there's got to be the same approach from senior people who, hopefully, would know a bit about it and junior people who wouldn't.... That it would be do this, do this, do this and so what I think should be done and probably most important in the non-research patients is having an algorithm with a referral pattern therein so everyone gets the same thing.... that's my answer to everything, is to protocolise it. And if you have that then even your junior members of staff will go and do that, you know, and they won't touch it otherwise. And also it's not as if the senior members aren't deficient as well. That would be my answer for any aspect of care that's poorly managed is to protocolise it and make sure the protocol works and to go with it, you know.”

[HCP03: Male clinical research fellow]

Two women and two partners also commented on their experience that this aspect of care was poorly coordinated.

"There didn't seem to be any coordination about how it [couple's sexual difficulties] should be approached or who should do it, or how it should be done or, you know, so obviously there is a bit lacking in that respect. But having said all that, I say what I said just now, that there's only one important thing really, there's only one important thing and she was delivered back to me as good as new and that's all I had to worry about, you know.”

[PTNR03: > 60 year old husband of PT07: 63 year old woman 12 months post chemo-radiotherapy / surgery for rectal cancer]

During interviews with patients and partners there was often a sense that the gratitude they felt to their treatment team for having helped them to survive the initial cancer threat made them more accepting of inadequacies in their health care management than might be encountered in patient populations where disability or threat to life was not such a dominant context.

As has been illustrated throughout this study, women with anal and rectal malignancies were considered to be particularly poorly served regarding the provision of feminine care advice, menopause management and guidance regarding female sexual difficulties when compared to their counterparts with cervical or endometrial cancer. Four health professionals spoke of the need to create an integrated service for women having
radical pelvic cancer treatment to incorporate those with rectal, anal and bladder malignancies.

"I think the problem might be that there aren't enough patients to warrant having a specific person. Because a lot of the patients we deal with are elderly and there's only a smallish number of patients who are GI who have rectal cancers or anal cancers, but maybe you could do it jointly with gynae, or something......there maybe could be a nurse who worked down here once a week or something and was at the gynaecology department the rest of the time, that would be good."

[HCP01: Female specialist registrar]

Colorectal nurse specialists did not normally have the clinical expertise to assess and manage radiation induced menopause, vaginal toxicity and sexual morbidity due to their focus on gastro-intestinal treatment side effects or on the surgical management of rectal or anal tumours. Furthermore, while it was accepted that there were inadequate numbers of women with non-gynaecological malignancies to warrant separate service provision, gynae-oncology nurse specialists were not funded and did not have the service capacity to offer their services to women unless they had a gynaecological cancer diagnosis.

"I see all patients having gynaecological malignancy, having pelvic radiotherapy for a gynaecological malignancy. I have been asked to see all patients having pelvic radiotherapy but I made it very clear when I first came here that I couldn't carry that caseload."

[HCP04: Female clinical nurse specialist in gynae-oncology]

Three nurses, two doctors and one therapy radiographer mentioned the need to improve women's access to clinical nurse specialists and to enhance continuity in relation to feminine care provision following completion of radiotherapy. It was felt this could be achieved through a range of strategies designed to raise awareness of specialist nurse's contribution to women's post-treatment support and to reduce the practice of doctors acting as gatekeepers for access to specialist nursing services.

"I used to call the clinic time support and rehabilitation and nobody came! ...I think people feel that it's a weakness perhaps to think that they need support and rehabilitation. But also maybe I wasn't specific enough, because that's fancy language for most. Now I've called it Treatment End clinic and I'm now getting a lot more response. And it's worked with the doctors as well. Because now they are sending me people, so it's really interesting......So I think the other thing is perhaps to try and wipe out some of the assumptions that perhaps other colleagues might make about who I need to see, because that's the other thing that's a problem."

[HCP04: Female clinical nurse specialist in gynae-oncology]
"Researcher: You appear very dependent on the capability of the medics to elicit a problem worthy of referral to you. How confident are you that that will happen?

HCP09: Not very confident at all. I mean I think what happens is, patients who are really difficult get referred, and then they are too difficult for me as well, you know, but you then end up with a very difficult patient who needs referral to some sort of specialist service, or who needs, you know, significant calming down....nothing in particular but time. When really, like I said, there are all these others who get nothing. And I'm not saying that these women don't deserve the time they get but had you seen them a little bit earlier it might have been a lot easier to manage their problems, for you and for them. You know, and there are some women who had serious, serious problems before [treatment] and none of us are going to make any difference."

[HCP09: Female clinical nurse specialist in gynae-oncology]

"If we were starting in the acute phase covering things a bit better, and for example on the consent form, the whole business of feminine care. And I find that it's kind of, you know, I've got to be the person in the [treatment] planning meeting that keeps, that remembers about feminine care.....it somehow isn't just, you know, even after sort of years and years it doesn't kind of just seem to be automatic....it's a bit hit and miss......it's almost, you know, what you need is a big stamp on the front of all female pelvic radiotherapy charts that says, you know, feminine care, what discussions have been had and have they had all the sort of literature?"

[HCP08: Female consultant clinical oncologist]

Although face to face consultations were the preferred consultation format for discussing women's sexual concerns, four women welcomed health professionals initiating telephone contact with them to ask about their sexual recovery and three women would have liked telephone contact numbers so they could initiate contact should they wish to do so.

"I don't know, maybe if they could do like a questionnaire thing that you could fill in while you are here and then one of the girls [nurses] could get back to you when you are at home. And it's just a telephone conversation and then, do you know what I mean?" [PT20: 33 year old woman 22 months post chemo-radiotherapy for cervical cancer]

"I think it's probably more useful to have somebody specifically calling you back. Perhaps even if it was just a phone call, you know, I think there should be some kind of permanent person or phone number that you can contact, even if it's not a sexual problem, you might have a small thing six months down the line and you think, well I don't want to bother my GP or I can't get an appointment when I want to and they are just going to say that we are not chemo specialists or whatever, and it would be nice just to ask one simple question on the phone and you find out, well that's normal, which is the main thing, that it's normal." [PT05: 36 year old woman 12 months post surgery / chemo-radiotherapy for cervical cancer]

Although only two health professionals mentioned the need to improve the content of printed patient information booklets, five women and two partners commented on the
inadequate level of detail regarding sexual difficulties within the patient information publications they had been given.

"...it would be better if there was a seminar and a lot more stuff written down about it [sexual issues] because I haven't found anything written about it from here [cancer centre], you know." [PT14: 63 year old woman 4 months post surgery / radiotherapy for endometrial cancer]

"You could almost have one [information booklet] on sex on its own, couldn't you?....A lot of people are, you know, willing to read something, or perhaps you could even have a question and answer page on it that people could ask and put in the nurse's book and you could receive a written reply.....certainly I think more needs to be done on it." [PT17: 67 year old woman 15 months post chemo-radiotherapy for bladder cancer]

Three women and one partner spoke more specifically of the need for more detailed practical information about resuming sex post-treatment, including information such as the time for the vagina to heal and the optimal time to attempt to resume sexual intercourse. Furthermore, two of the five male partners interviewed (PTNRs 01 and 03) felt that they would like information made available that specifically addressed the potential difficulties encountered by male partners in responding to sexual changes that may be experienced as a result of treatment.

In terms of clinical practice development, health professionals suggested two strategies that they felt would improve the discussion and clinical assessment of treatment related sexual difficulties. The first suggestion related to the inclusion of vaginal stenosis and sexual difficulties as potential late effects in recognition of their omission from existing structured consent forms (n = 4 doctors at site A only) despite being common problems for women.

"Researcher: If you were re-designing your consent forms to include something slightly more detailed what would you consider to be the things that really should be in there that maybe aren't explicitly stated right now?
HCP08: Well I think that the sort of easiest parts are around the physical, kind of immediate physical, well not immediate, but the sort of obvious physical changes around vaginal changes in terms of shortening and narrowing and those sorts of things, I think that needs to be in. And I think that there does need to be something about libido and the just general sort of changes in the tissues in the area that might affect, you know, pleasure."

[HCP08: Female consultant clinical oncologist]

The second modification to clinic documentation proposed by five health professionals and four women was the introduction of a brief patient self-administered questionnaire that
could be completed by women as they waited for their follow-up consultation. This could then be used to guide the subsequent discussion with their medical team, making the consultation process more patient-centred.

"I don’t think the way we approach it is adequate at all because it’s not something that we think about all the time and we often forget about it [sexual concerns]. I think the way to broach it, I’ve certainly seen for example in the breast clinic that concentrated on menopausal symptoms is giving them a sheet with questions and tick boxes. So asking a lot of questions about vaginal dryness, pain on intercourse, all those sorts of questions they have to tick and then they give, they do it in the waiting room and they bring it in and give it to you and you see they’ve ticked ‘Yes’ for loads of things that they would probably never have admitted to you and you probably wouldn’t have asked. And actually that really opens up a can of worms.”

[HCP06: Female specialist registrar]

“Sometimes I think it might help if you did have more of a structured questionnaire looking thing so that people would realise that this [sexual difficulties] isn’t uncommon. You have to weigh this is quite a normal thing to have, versus you’re an individual and I want to treat you as an individual……so that you could bring a routine questionnaire onto a personal level. Because if I just give somebody a questionnaire, I mean she doesn’t even know if I’m going to read it. But if I had something that’s more structured but it’s something a bit like this [research interview] where it gives you openness to discuss about each question, qualitative and quantitative, then yeh, it could help.”

[HCP17: Female therapy radiographer]

“...I mean perhaps the idea would be while you are waiting to go into the clinic to have a little questionnaire about how you are feeling......That you could give to them [clinic staff] and then they could sort of look at it and, ehm, because you are sitting there doing nothing, you know, and although it would put a bit more pressure on them to read it through, it might be reassuring and a lot of people don’t mind looking at things and writing do they? Where they’d be reluctant to actually say something [about sexual concerns].”

[PT17: 67 year old woman 15 months post chemo-radiotherapy for bladder cancer]

Health professionals involved in the gastrointestinal follow-up clinics had already noted that completing clinical trials questionnaires focused on female sexual dysfunction had increased the likelihood that they would ask women about the sexual consequences of pelvic radiotherapy during follow-up clinics.

10.4.1 Women’s preferred content of sexual health assessment during follow-up

Women were asked specifically what they would like to see included in any clinical assessment of sexual difficulties following cancer treatment. Although the majority of
women appeared to find it difficult to think of issues they felt health professionals should ask them about, nine women and one partner offered specific suggestions about what they felt health professionals should ask regarding this aspect of post-treatment recovery.

Only four items were recommended by two or more participants, but a total of sixteen different items were suggested as content ranging from enquiry about sexual pain, vaginal healing times and sexual aids for single women to questions about desire and orgasm, ease of dilator use and the importance of sex to the couple. Perhaps unsurprisingly, closer scrutiny of these assessment elements often revealed a relationship between the woman or partner's personal experiences of sexual difficulties post-treatment and their suggested content for sexual health assessment.

The four items suggested by a number of participants were:

- Requesting information about the woman's current relationship
- Asking about fear of resuming sexual intercourse
- Asking about different types of sexual problems encountered after treatment
- Asking about changes in sexual behaviour following treatment

"To definitely take it out of the medical context and put it into more of like a relationship context of how, you know, how's the treatment impacted and just how would she feel about being a woman. That could be a kind of like starting point; I mean maybe for some people talking about sexual stuff can be quite difficult, it's a very personal area and maybe some people, if they are having problems that they don't want to disclose, feel that embarrassed or confused about it so maybe even something quite as ....gentle as that.....I wouldn't have been opposed at all or felt uncomfortable about there being some sort of question about, you know, do you need to talk to anyone about your sexual relationship at all, or any fears that you have got, anxieties about maybe resuming a sexual relationship again? Maybe sort of phrase it in a few different ways because someone may not answer a direct question about their sexual thing but might bring it up in relation to their identity as a woman." [PT12: 42 year old woman 14 months post chemo-radiotherapy for cervical cancer]

10.5 Category Summary

Overall participants made a number of suggestions for practice developments that they believed would improve the currently inadequate and ad hoc approach to the clinical assessment of female sexual morbidity after pelvic radiotherapy.

Women appeared to want closer engagement of their intimate partners in discussions about sexual difficulties while health professionals expressed mixed views that seemed to be based on a lack of confidence in managing the dynamics of sensitive discussions with
couples as opposed to individual patients which was the normal focus for their consultations.

The optimal timing of conversations about potential sexual difficulties associated with treatment was experienced by health professionals and women as particularly problematic. This appeared to emanate from the clinical context of cancer as a life-threatening illness together with the burden of patient information women received at the time of treatment consent and the physical and emotional burden of acute treatment effects.

The majority of women expressed a preference for the discussion of sexual issues once their treatment had been completed, with some suggesting a need to revisit this topic at multiple points before, during and after treatment to monitor for the development of difficulties across time. However, the diversity of individual women's stated preference for such information provision poses a challenge for the delivery of individualised care within a health care system that tends towards standardisation to avoid care omissions.

In choosing who was felt to be the most appropriate person to help women with their sexual concerns, disciplinary background and expertise appeared to be less important than rapport and trust. Some women reiterated their preference for a female practitioner that could offer them practical advice, leading to the suggestion that a specialist nurse may be more suitable than medical staff whose focus was more on disease surveillance and acute treatment management. Overall women wanted to see someone linked with their treatment team or hospital Trust as opposed to a specialist or counsellor external to the cancer centre.

Doctors, therapy radiographers and radiotherapy department nurses tended to see the clinical nurse specialist as the principle point of contact and referral unless there was a specific physical problem to resolve in which case referral back to the woman's treatment team or to a gynaecologist was preferred. There were mixed opinions about the use of the woman's general practitioner (GP) as a source of onward support regarding sexual matters. Clinical nurse specialists referred women to medical and nurse specialist colleagues within the cancer centre and also accessed specialist psychosexual or relationship counselling services beyond their immediate hospital Trust.

The most popular service change suggested by health professionals and women was the establishment of a separate clinic to address psychosexual difficulties associated with treatment as it was felt that routine medical follow-up clinics was not a conducive environment for these sensitive discussions. Other health professionals suggested the
establishment of clear referral pathways and levels of service provision for these women and linking care pathways to treatment protocols or clinical algorithms would reduce care omissions and improve overall standards of assessment and management. Improvements to care documentation and the level of detail contained within structured consent forms and patient information booklets were also made by both women and health professionals. In particular the introduction of a patient-self-administered questionnaire in the clinic setting was proposed to ensure sexual concerns were more readily raised by reluctant or embarrassed patients and health professionals alike where questionnaires could be used to guide follow-up consultations.

A number of women also suggested specific content for brief questionnaires about sexual issues or health professional enquiries that included details about the woman’s current relationship context, fears about resuming intercourse, types of sexual difficulties encountered and changes in sexual behaviour post-treatment.

These proposed changes to individual practice or to wider service developments proposed by health care practitioners, women and their partners are all possible within the boundaries of existing staff resources and current budgetary constraints. What is urgently required is an acknowledgment that current inadequacies in meeting the needs of women whose sexual lives have been adversely affected by their cancer treatment are not acceptable in contemporary UK cancer survivorship and rehabilitation services. This point and other key findings from the preceding thesis chapters are further explored and evaluated in light of the published literature in the discussion chapter that follows.
Chapter 11: Discussion of Findings

"...in the innumerable words spoken by men - whether they are reasonable or senseless, demonstrative or poetic - a meaning has taken shape that hangs over us, leading us forward in our blindness, but awaiting in the darkness for us to attain awareness before emerging into the light of day and speaking. We are doomed historically to history, to the patient construction of discourses about discourses, and to the task of hearing what has already been said”

(Foucault, 1973: xvii)

11.1 Introduction

The overall aim of this ethnography was to explore current approaches to the clinical assessment of female sexual difficulties associated with radical radiotherapy for the treatment of pelvic malignancy. Furthermore, a specific aim of this study was to develop an integrated physical and psychosexual assessment methodology that could be used in routine clinical practice to improve the evaluation of female sexual difficulties associated with pelvic radiotherapy.

The context for this study was that of medical follow-up within clinical oncology and the perspectives of women, their partners and relevant health care professionals were sought. This focused ethnography explored the organisational, practitioner and patient factors that influence both the content and conduct of women's sexual health assessment in clinical oncology practice.

As discussed in section 2.2, essentialism remains the dominant philosophical foundation for positivism and for the study of sexuality within biological and medical sciences comprising sexology (Vance, 1991; DeLamater & Shibley Hyde, 1998). In contrast, social scientists interested in the field of sexuality have often taken social constructionism as their theoretical paradigm and have used research methodologies, such as ethnography, that are congruent with this theoretical standpoint. Interpretation of the findings of this study are most fully understood through the theoretical perspective of social constructionism (Berger & Luckmann, 1967) and more specifically the work of Michel Foucault (1973, 1990a, 1990b, 1992). In considering Foucault's (1990a) contribution to social constructionism and the study of sexuality DeLamater and Shibley Hyde (1998: 15) claimed that:
"...sexuality is not an essence. It is not a biological quality or natural inner drive whose character is the same across time and space. It is a cultural construct. Its meaning is derived from language or discourse; each institution in society has a discourse about sex, a way of thinking and talking about the broad array of behaviours and actors who are involved in sexual expression."

Despite these authors’ assertion that sexuality is socially constructed I would argue that it would be theoretically and clinically naive to suggest that sexuality and its expression has no biological or material basis. Even Berger and Luckmann (1967:181) recognised that sexuality had “biological drives” but argued that these drives combine with socio-cultural and historical factors to shape the nature and meaning of sexual expression at both an individual and societal level.

Both Berger and Luckmann (1967) and Foucault (1990a) spoke of the importance of language or “discourse” in both constructing and communicating shared meanings about sexuality and sexual expression. As will become apparent later in this chapter, not only is language used to construct sexuality and its boundaries but the omission of discourse about women’s sexual concerns from medical consultations exerts a powerful influence on the construction of female sexuality in the oncology clinic as experienced by women and their partners.

Fundamental to any meaningful exploration of the clinical assessment of female sexual difficulties arising from pelvic radiotherapy must be an understanding of the ways in which female sexuality is constructed within the context of cancer as an illness. Foucault’s work on medical perception, *The Birth of the Clinic* (1973), explored how taken-for-granted *scientific facts* that underpin our understanding of the body, its functions and its disorders can be re-interpreted in light of an evolving socio-historical understanding of the field of medicine. What emerges, as illustrated by the data discussed in section 7.4: Vagina Monologues, is that medical knowledge considered to be scientific fact in any given historical period is framed by a specific biomedical understanding of illness that simultaneously excludes alternative explanations, notably those arising from psychological and sociological perspectives (Cheek & Porter, 1997). As Cheek (Cheek & Porter, 1997) explains, Foucault (1973) drew attention to the ways in which dominant biomedical discourses about the body and the nature of illness were also manifestations of the relationship between power and knowledge “...that both produces and maintains such dominance.” (Cheek & Porter, 1997:109).
"...the medical gaze was also organized in a new way. First, it was no longer the gaze of any observer, but that of a doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention."

(Foucault, 1973:109)

Application of a Foucauldian analysis to the structures and processes of the oncology clinic enables us to consider that the dominant biomedical discourse in Western medicine represents only one of a number of discourses that contribute to our understanding of the nature of cancer, its treatments and the consequences of both illness and treatment for patients and their families. Foucault's (1973) critique of the power inherent to medical knowledge is not advocating a rejection of biomedicine. On the contrary, his ideas suggest that attention is paid to the consequences of applying a narrow biomedical lens to assessment and management of the complex, multi-faceted human phenomena encountered in clinical practice, such as sexuality. Hence the ways in which female sexuality is constructed by health care professionals and by women experiencing cancer therapy first hand can only be partially defined by the anatomical and functional changes observed and more commonly discussed in the clinic. A broader analysis reveals the diversity of meaning ascribed to these changes by women and their partners, particularly when consideration is given to their implications for patient's sexual relationships as explored through in-depth interviews with women and their partners in this study.

Despite the utility of Foucault's ideas in identifying the power of dominant discourses inherent to social structures such as religion and medicine that shape our understanding of the human condition, Porter forcefully argued that Foucault fails to offer insights as to how one might subvert "...the authority of experts by exposing the power that grounds their supposedly neutral knowledge..." (Cheek & Porter, 1997:111). Furthermore, in considering the contribution of Foucault's ideas for nursing and health care, Porter questions the capacity of such analyses to offer alternative discourses that embrace patients' multiplicity of needs any more convincingly than biomedical reductionism.

As discussed in section 2.2, radical social constructionism, of which Foucault may be considered a proponent, has been criticised for its unwillingness to acknowledge the existence of any objective facts within our social world (Giles, 2006). Social constructionism may thus be a difficult philosophical or theoretical position to maintain when the epistemological basis of sexology requires an integration or synthesis of the physiological, anatomical, functional, psychological and sociological aspects of human
sexuality in order to fully comprehend the nature of sexual difficulties experienced in health and illness.

What appears clear is that excessive reliance on any single theoretical perspective to explore the complexity of human sexuality is likely to result in an incomplete picture being revealed. In conducting this ethnographic study of female sexuality in oncology I have come to recognise some limitations in Foucault’s ideas about sexuality (1990a, 1990b, 1992). I have listened to personal accounts of women’s altered sexual lives that were not only socially constructed, but embodied other realities incorporating the anatomical, physiological and functional changes created by their cancer treatment. Hence, as illustrated by DeLamater and Shibley Hyde (1998), some aspects of human sexuality such as sexual desire, satisfaction or orientation may be better understood using a combination of both essentialist and social constructionist perspectives to explore the complex abstract elements of human sexuality.

Critical realism may offer an alternative solution to the tension created by trying to combine or integrate essentialist and interpretive concepts. Critical realism, as developed by British philosopher Roy Bhaskar, recognises that “...there are objects of knowledge that exist independently of that knowledge.” (Porter, 1998: 171). In contrast to social constructionism, critical realism acknowledges that there are patterns of behaviour that occur as a result of inherent social structures. These social structures operate within society and evidence of their influence is manifest through repeated observation of common patterns of human action or behaviour.

There is some overlap with social constructionism in that these social structures are not independent of the individuals they influence “...rather they are maintained or transformed by the actions of individuals. Thus the relationship between structure and action is a two-way process.” (Porter, 1998: 173). Critical realism also asserts that “reality” is comprised of a number of inter-related layers that emerge from the relationships between elements of society operating at a more fundamental level. Hence although “...the structural level of society emerges from social interaction, it has powers and properties that are ‘relatively autonomous’ from that action.” (Porter, 1998: 173). As encountered in this study, the heteronormativity of human societies may be seen as an example of a social structure that influences the dominant modes of sexual behaviour revealed to social researchers as part of that society.

As evident from the literature reviewed in chapter two of this thesis, adopting solely a biomedical / positivist or a social constructionist / interpretative stance in the study of
human sexuality has, thus far, created a polemic that has not served the complexity of female sexuality well to date. This may, in part, explain the paucity of quality research that informs the management of organic sexual dysfunction in women following cancer treatment (Denton & Maher, 2003; Miles et al. 2007). Hence this ethnography departs from previous research in the biomedical and social sciences in offering an integrated or "conjoint" approach to the study of female sexual difficulties after pelvic radiotherapy.

This study explored multiple realities or perspectives on female sexual difficulties after pelvic radiotherapy through the domains of literature reviewed and through the analysis and interpretation of data capturing the diverse perspectives of health professionals, women and their partners. Synthesis of the literature and triangulation of this data permit the reader to explore each reality or perspective in its own right as well as to consider elements that offer corroborating or conflicting perspectives. In this way a broader and more comprehensive understanding of women’s sexuality following pelvic radiotherapy is constructed than would be obtained through the narrow lens offered by any individual perspective.

The data from this study reveals the socially constructed nature of female sexuality as manifest through three core categories that encapsulate the social structures (or culture) of the clinic, its processes (the biomedical gaze) and health professional discourse about female sexuality ("Talking Sex" in the clinic) in oncology. However, a tension exists in data that also contains ample evidence of the objective reality of women’s symptoms (for example, vaginal bleeding or stenosis) and in so doing demands an integrative approach to both data interpretation and any resulting practice development.

The diversity of perspective offered by this thesis is one of its theoretical and clinical strengths in encouraging greater integration and synthesis of knowledge about the nature and meaning of female sexual difficulties after cancer therapy and the challenges inherent to clinical assessment of what remains a complex and under-researched domain of clinical practice in both oncology and sexology.

The presentation and discussion of key findings in this penultimate chapter is structured around the emergent core data categories arising from the research questions as follows:

- **The Culture of the Clinic**: How does the environment and conduct of radiotherapy clinics influence communication about sexual issues between women, their partners and health care professionals?
- **Constructions of Female Sexuality after Cancer Treatment**: *What are the nature and meaning of sexual difficulties experienced by women who have completed pelvic radiotherapy?*

- **Talking Sex in the Clinic**: *What is the feasibility of using an integrated psychosexual assessment strategy in routine follow up and what are the core elements of such an assessment strategy?*

Throughout this chapter discussion of the study findings represents an integration of study data emanating from both the participant observation and interview elements of this ethnography. Of the three core data categories outlined, "The Culture of the Clinic" emerged from combined data, whereas the remaining two categories emerged solely from interview data. Where analysis and triangulation of the data reveal conflicting findings, the specific data type and source is identified.

### 11.2 The Culture of the Clinic

The oncology follow-up clinic was viewed by health care professionals, women and their partners as a time limited, medically led service where the dual priorities of disease surveillance and management of acute treatment side effects dominated. Doctors in the clinic adopted a *clinical gaze* (Foucault, 1973) focused on detecting physiological and anatomical abnormalities in the woman’s pelvis induced by either the illness itself or by treatments used to eradicate or control her cancer. The biomedical focus inherent to medical practice was manifest through analysis of both participant observation data and interview transcripts from women, their partners and the health professionals who took part in the study.

While the clinical gaze emanates from medical practice, it was reinforced through the practice focus of therapy radiographers and nurses in the radiotherapy departments. As will be discussed later in this chapter, medical staff’s dominant biomedical view of women’s recovery after cancer was endorsed by expectations expressed by the majority of women and partners who took part in this study.
Objectification of the body through application of the clinical gaze and associated diagnostic processes (Foucault, 1973) inevitably leads to exclusion of the psychological and social elements of the illness experience. Lawler (1991) applied Foucault's (1973) discourse about medical power and the exertion of social control over the body to the practice of nursing and associated body work. She argued that nursing and medical power was exerted through the processes of surveillance, discourse and the application of professional knowledge. These processes were central to the construction of a system of norms created by "experts" that determined which patient and illness related concerns were deemed legitimate to address within mainstream medical and nursing systems and which concerns were banished to the margins of health care practice.

As Foucault explains:

"...in clinical medicine, to be seen and to be spoken immediately communicate in the manifest truth of the disease of which it is precisely the whole being. There is disease only in the element of the visible and therefore statable."

(Foucault, 1973: 116)

The clinical gaze operates to make visible certain aspects of a patient's ill-health and through visibility the problem or dysfunction is defined by available language, becomes part of medical discourse and once identified and defined by that shared system of meaning, can be acted upon through medical intervention. A consequence of the selective clinical gaze and dominant biomedical discourse operating in this study was that treatment related female sexual difficulties were rarely discussed during medical or nursing consultations (24.6% of observed consultations) and thus women's psychosexual needs remained largely invisible and marginal to medical and nursing legitimacy. Arguably it is more difficult to see certain types of female sexual dysfunction due to their abstract and private nature. As will be discussed later in this chapter, while radiotherapy induced vaginal changes could be visualised directly through the clinical gaze, changes in sexual desire, arousal, orgasm, satisfaction or women's experience of sexual pain remained hidden, perhaps requiring a wide-angled lens to make them visible and thus heard or "statable" within the clinic (Foucault, 1973).

The failure of health professionals to routinely include questions about treatment induced sexual morbidity as a legitimate aspect of medical follow-up also reduced the likelihood that women would initiate questions about sexual recovery with their treatment team. From a Foucauldian perspective this may be considered evidence of self-censoring behaviour where women did not address topics that were excluded from medical discourse.
and thus lacked legitimacy. The absence of enquiry about sexual recovery was taken by women to mean that their sexual well-being was unimportant to doctors (see section 9.1.2) especially in the context of effective control of their cancer (Hordern & Street, 2007a). Indeed a number of women interviewed did not consider the discussion of treatment induced sexual difficulties to fall within the remit of their oncologists, who they primarily associated with ensuring their survival in the face of the existential threat posed by cancer (Butler et al. 1998). The marginalisation of female sexual difficulties associated with cancer treatment was not only evident through participant observation in the clinic and women’s narratives about the practice of individual health care professionals, but was also recognised by women to exist at a systemic or organisational level within the cancer centre. A number of women in the study commented on the limited availability of and lack of detail in both verbal and written patient education about sexual difficulties when compared to information given to them about other side effects (bowel, bladder and skin) of pelvic radiotherapy (Faithfull & White, 2008).

When the clinical gaze turned towards women’s bodies in the oncology clinic, it commonly did so through the lens of treatment induced vaginal toxicity and the maintenance of vaginal patency through vaginal dilator use. As discussed in chapter five, vaginal toxicity was observed as a discussion topic in only 42% (n=29) of observed clinical consultations, compared to enquiries about bowel and bladder toxicity in 81% and 70% of consultations respectively. Where scrutiny of radiation induced vaginal changes had the potential to lead to exploration of sexual implications for the woman, this occurred in only 17 out of 29 observed consultations. Despite the relatively low level of discussion about vaginal toxicity in the clinic, women spoke at length in their interviews about the perceived and actual vaginal changes they had come to know through patient initiated discussions with individual health professionals, reading materials and their own bodily experiences (see section 7.4: Vagina Monologues).

As mentioned previously, while the vagina is clearly an anatomical and material entity, women, men and health professional’s experiences of the vagina and associated meanings are also constructed and interpreted within their socio-cultural and historical contexts (Braun & Wilkinson, 2001). Some of the women in this study (PT01, PT03) had graphically reconstructed the personal meaning of their vagina as a consequence of their illness experience. The processes of cancer diagnosis, treatment and medical follow-up appeared to transform the vaginas of some women from a private, intimate and taken for
granted part of her body to a source of dis-ease, abnormal bleeding, discharge, pain, fear of death and sense of intrusion. Braun and Wilkinson (2001:18) offer an interesting socio-cultural analysis of how the vagina has been represented in both lay and academic contexts across time. In exploring the symbolic meaning of the vagina (here this term incorporates any reference to female genitalia and not solely the vagina itself) these authors offer seven enduring representations, namely:

- The vagina as inferior to the penis
- The vagina as absence
- The vagina as (passive) receptacle for the penis
- The vagina as sexually inadequate
- The vagina as disgusting
- The vagina as vulnerable and abused
- The vagina as dangerous

Within this study (section 7.4: Vagina Monologues) there were a number of examples within the data of negative representations of the vagina. PT03 (a lady treated by radical hysterectomy and radiotherapy for endometrial cancer) spoke of how her invisible or hidden vagina (the vagina as absence) had been surgically shortened without her explicit knowledge. In expressing her anger she compared her experience to the surgical removal of a third of a man’s penis and questioned whether such a surgical act would be carried out with such disregard to the relative importance accorded to this element of male anatomy. PT01 (a lady treated with chemo-radiotherapy for cervical cancer) expressed personal disgust through the imagery she had constructed around her vagina as a “small shrivelled thing” following her radiotherapy and found it difficult to cope with the revulsion (the vagina as disgusting) she felt at not only her knowledge of treatment induced vaginal changes but also the fact that her vagina now represented a source of danger, having become a route for future sexually transmitted encounters with human papilloma virus and cervical cancer. The vagina was viewed by some health professionals as a source of unpleasant discharge and blood arising from the disease process and women were taught to perform “feminine care” that involved the daily use of vaginal douching to cleanse the vagina of unpleasant secretions (the vagina as disgusting) despite the absence of any evidence base to support the benefits of vaginal douching (Braun & Wilkinson, 2001).
Paradoxically, in the clinic the vagina appeared to inhabit both public and private domains simultaneously. For women with cervical or endometrial cancer the vagina was made public by routine medical surveillance at each follow-up appointment through performance of vaginal examinations (VE), while at other times (PT03) the vagina remained invisible. The relative invisibility of the vagina was perpetuated through failure to mention vaginal fibrosis or stenosis in structured treatment consent forms [research site A] for external beam radiotherapy or vaginal brachytherapy in gynaecological malignancies, despite this being a common treatment late effect cited within the literature (Denton & Maher, 2003; Brand et al. 2006; Bruner et al. 2006). Vaginal changes were omitted from structured consent forms given to women treated for anal, rectal or bladder cancer with chemo-radiotherapy. This was an interesting omission given the routine inclusion of radiotherapy induced menopause and infertility as side effects of radical pelvic irradiation in all the structured consent forms reviewed. Perhaps understandably, irreversible damage to women's reproductive function was considered such a serious consequence of pelvic radiotherapy that all pre-menopausal women had to be made aware of this certainty before giving informed consent to treatment. Yet it could be said that inadequate information about changes to a woman's vaginal anatomy, function and failure to mention sexual difficulties that can arise as a result of radiotherapy serves to further undermine the importance of women's knowledge of their genital anatomy in both illness and health as well as serving to disregard women's sexual identity and well-being after cancer. As Braun and Wilkinson (2001:26) argue:

"The idea of the vagina as something private, shameful, or not talked about can affect women's willingness not only to discuss symptoms, or to seek medical help if needed, but even to examine, and thus 'know', their genitals. Knowledge is important in distinguishing what is 'normal' and 'healthy' for the genitals and what is not normal and thus what constitutes a potential health risk."

In this study the vagina was particularly invisible in the follow-up of women after treatment for rectal, anal or bladder malignancies where vaginal examination was not routinely performed. In exploring this omission with medical staff who worked with these women it became clear that the main purpose of routine vaginal examination (VE) in oncology follow-up was that of disease surveillance (for gynaecological malignancies) and not principally to monitor the prevalence of vaginal toxicity associated with pelvic radiotherapy. With the exception of the gynaecological follow-up clinics, VE was only performed when women volunteered they had experienced abnormal vaginal symptoms.
Medical staff interviewed in this study acknowledged that levels of awareness about the prevalence of radiation induced vaginal changes and the profile of female sexual morbidity was even lower in gastrointestinal or urology settings (see section 9.1.4) than in the gynaecological follow-up clinic (Hendren et al. 2005).

Women's vaginas appeared to be objectified and de-sexualised by women and health care professionals as a way of coping with the intrusive technical interventions necessary for what was considered the effective clinical management of their illness (Stewart, 2005). Technical interventions involving instrumentation of the vagina included the placement of vaginal applicators for the delivery of brachytherapy, the performance of speculum examination of the vagina during follow-up and further objectification of the vagina as a passive receptacle for plastic phalluses through women's use of vaginal dilators following treatment completion. Objectification of intimate health care interventions, examinations, or body parts through the use of sanitising language and other distancing techniques were commonly employed by both health professionals and patients to reduce embarrassment and discomfort arising from any sexual associations (Lawler, 1991; Stewart, 2005). Another example of such distancing tactics in this study was found in the sanitised language used by nurses and therapy radiographers to teach women vaginal dilator use. The use of vaginal dilators by women to maintain vaginal patency after pelvic radiotherapy was normally referred to as "feminine care". Dilator use was usually taught to women in a somewhat technical manner, avoiding the use of sexual language where possible (Weijts et al. 1993; Stewart, 2005), as opposed to being integrated with patient education related to women's sexual concerns or future sexual recovery. Typically women were taught about the rationale for and technique of dilator use during a five or six week period of radiotherapy delivery when they were understandably focused on surviving the rigours of treatment and acute side effect management. This willingness to divorce the use of vaginal dilators from any intimate association with the sexual connotations of their use may be partly explained by the timing of such discussions within the woman's treatment journey.

Evidence of the relatively low priority accorded to the promotion of women's vaginal health after pelvic radiotherapy was found at both individual practitioner and organisational level and included absence of a systematic approach to the evaluation of vaginal dilator provision and patient compliance.

A lack of staff continuity meant that health professionals teaching the procedure of vaginal dilation were not in contact with women to subsequently identify difficulties.
experienced with dilator use, intervention compliance or to enquire about a woman's sexual recovery after treatment (Juraskova et al. 2003; White & Faithfull, 2006). This lack of routine enquiry about the prophylactic use of vaginal dilators occurred despite anecdotal evidence from medical, radiographer and nursing staff that women did not tend to persist in their use of dilators over time post-treatment (Robinson, Faris & Scott, 1999; White & Faithfull, 2006). In the follow-up clinic medical staff did not routinely enquire about dilator use among women recovering from pelvic radiotherapy unless a vaginal change such as adhesions, stenosis or spontaneous bleeding was detected during vaginal examination. The assessment of treatment-induced vaginal changes, their prevention and management did not appear to be accorded the same importance within the clinic as treatment late effects affecting a woman's bowel or bladder. As the role of the vagina in childbirth was no longer relevant as a consequence of treatment induced menopause, it appeared as if the vagina was not considered an equally important structure in the context of female sexual expression. Through the clinical gaze, women's vaginas were either invisible or through medical and patient surveillance, were viewed as a source of matter out of place (bleeding), pain, disease and threat to life (Braun & Wilkinson, 2001). Medical staff's focus on vaginal pathophysiology, while failing to routinely enquire about women's use of vaginal dilators or to discuss the implications of vaginal changes for women's sexual recovery, reinforced the low priority accorded to women's vaginal and sexual health within the dominant biomedical discourse of the cancer centre (Foucault, 1973).

Paradoxically, despite the lack of a systematic approach to vaginal dilator management, a number of health professionals saw the delivery of patient education about the use of vaginal dilators as an opportunity to offer women information about the sexual consequences of pelvic radiotherapy. As will be discussed later in section 11.4, doctors reported that questioning women about their use of vaginal dilators was sometimes used as a means to legitimise asking them about whether or not they had been able to resume sexual intercourse. In establishing links between vaginal toxicity, dilator use and resumption of sexual intercourse it could be argued that women's sexual lives were further medicalised through framing sexual intercourse as merely another means to maintain vaginal patency and to reduce treatment induced vaginal changes as opposed to considering the broader emotional and symbolic meaning intercourse might hold in women's recovery after cancer.

During the analysis and interpretation of these study findings, in my roles as both researcher and cancer nurse, I found that I readily concurred with the views expressed by
the women, partners and professional colleagues who contributed to this study. Ensuring women's survival and managing treatment side effects that impacted on women's quality of life after cancer remain clinical objectives of paramount importance and are not in dispute through this analysis. What is open to professional debate, however, is whether or not there is also a moral imperative, having "cured" women of their pelvic cancer, to provide a clinical service that can address the treatment late effects that arise as a consequence of successful disease control? As found in the recent Australian study by Hordern and Street (2007a), focusing on the importance of survival and patients' expressed desire to have their sexual recovery recognised as a relevant health care goal should not be seen as mutually exclusive. A commitment by professionals to engage both the biomedical aspects of illness and the socially constructed nature of individual women's experiences may enable these contrasting illness concepts to live in creative tension within the practice reality of the oncology clinic.

Conventionally, nursing rhetoric has argued that nurses provide a service that is holistic and more likely to incorporate the psychosocial, and thus psychosexual, aspects of women's illness experience. However, as Allen's (2004) analysis of ethnographic research about nursing work over a decade (1993-2003) revealed, contemporary nursing ideologies emphasising holistic, individualised care that is responsive to patient's psychosocial as well as physical care needs are far removed from the realities of contemporary British nursing practice. These field studies demonstrated that nurses acted more as health care mediators to ensure the smooth running of health care systems. In providing care to individuals, much of nursing work was considered to be "...task based and fragmentary..." and nursing assessment was conducted in ways that were "...perfunctory in nature...". This review also found that far from promoting individualised care, standard operating procedures and care templates were an increasing feature of the care systems in which nurses worked (Allen, 2004: 274).

A more recent study that explored "the nursing voice" in clinical documentation (Abbey et al. 2005:69) found that patient "...complaints of a psychosocial nature were also handled in a technocratic fashion..." and pharmacological interventions such as anxiolytics or anti-depressants were sought as pragmatic solutions to psychological distress as opposed to nurses engaging in non-pharmacological support strategies. In contrast to expressed notions of holism, nurses contributed to fragmentation of the patient through initiation of referrals to a number of different specialists to deal with patient's "broken
down parts" (Abbey et al. 2005:71). Contrary to the aspirations of nursing theory that promote holism, professional autonomy, patient partnership and self-determination, data to support this model of nursing practice was sparse compared to evidence of biomedical dominance in the framing and documentation of nursing interventions (Abbey et al. 2005). While these authors acknowledged that documentation does not necessarily equate with actual practice or care delivered to patients, what was apparent was the invisibility of nursing practice that supports patients in the emotional and personal experience of their illness. Perhaps the “invisibility” of these socially constructed elements of nursing philosophy and care in current health care systems is maintained because practitioners are not educated or supported to identify and value the domains of knowledge and praxis that lie beyond the boundaries of biomedicine?

The somewhat technocratic nature of nursing described in these published studies (Allen, 2004; Abbey et al. 2005) was witnessed directly in the participant observation of nursing work that took place in the follow-up clinics and radiotherapy department of this study. Nurses who worked in the out-patient clinics were usually less experienced or more junior within the nursing hierarchy and their roles were predominantly to prepare the equipment and supplies in the clinic rooms and to ensure the smooth movement of patients and doctors between the various consultation rooms. The nursing activities that took place were of a somewhat rudimentary nature, such as assisting patients to dress/undress, collecting specimens or performing a wound dressing. In the interviews a number of the women (PT03, PT12, PT14, PT19) commented on their experience of the somewhat restricted and relatively unskilled care delivered by specific nurses in the radiotherapy department (research site A).

Of the four clinical nurse specialists who were interviewed in this study (HCP 04, 09, 10, 12) two commented on the ways in which biomedical dominance shaped the way patient’s clinical difficulties were viewed and managed within the cancer centre. Only HCP04’s interview transcript demonstrated broader knowledge and professional confidence in proactively assessing and intervening in relation to the emotional, relationship and physical elements of women’s sexual difficulties after treatment. These findings suggest that the role of the clinical nurse specialist is more often that of supplementing or substituting medical staff functions as opposed to offering a care approach that is complementary to biomedicine and technology (Faithfull & Hunt, 2005; Aranda & Jones, 2008).
The contribution of specialist nursing to the care of women who received their radiotherapy treatment as outpatients appeared to be limited in this study. In site A the nursing role during treatment consisted of the provision of “feminine care” and the monitoring of acute dermatological, gastrointestinal and urological side effects until the women completed their five to six week course of radiotherapy treatment. In site B this role was provided by therapy radiographers and there was no routine nursing presence in the radiotherapy department. Organisational structures influencing the delivery of support services after cancer treatment created circumstances whereby specialist nurses, particularly clinical nurse specialists, were not routinely present in either the radiotherapy department or outpatient clinics. Paradoxically, medical staff relied on clinical nurse specialist colleagues as the principal source of expert knowledge and onward referral for assistance with women where specific sexual concerns had been identified (see section 10.3).

Although clinical nurse specialists were considered the first point of contact for the clinical management of women with sexual concerns arising from radiotherapy treatment, they did not have direct access to the majority of women attending the radiotherapy department as outpatients. Clinical nurse specialists were therefore reliant on referrals from colleagues or receiving a direct enquiry for women themselves. Patient self-referrals seemed unlikely as the majority of women and partners interviewed were unaware of the presence of clinical nurse specialists within the cancer centre and unsure about whom to contact (see section 9.1.1) regarding sexual concerns in the absence of contact details within the treatment team or cancer centre to address this type of problem or difficulty.

Despite the low level of enquiry about sexual difficulties by medical staff in the follow-up clinic, they appeared to act as gatekeepers for the referral of women with sexual concerns to clinical nurse specialists. While two of the clinical nurse specialists who took part in this study lamented this situation (HCP04 and HCP09) it was apparent that these specialist nurses remained largely constrained by the structures and hierarchies within which they worked and had become “...subjects responsible for their own subjection.” (Wheatley, 2005:439).

Nurse specialists and therapy radiographers working with women treated for anal or rectal cancer also regarded gynae-oncology nurse specialists as the source of expertise about female sexual difficulties within the cancer centre (see section 10.3). This proved problematic for gynae-oncology nurse specialists because their workload was such that they could not provide a service for all women receiving pelvic cancer treatment. Specific
resources had not been made available within the cancer centre to address the sexual rehabilitation needs of women with a non-gynaecological cancer diagnosis. It could be argued that despite women with ano-rectal or bladder malignancies having comparable information and support needs regarding their sexual recovery to women with gynaecological malignancies, this service omission is another example of the invisibility of female sexual difficulties for this specific patient group. Reliance on clinical nurse specialists in gynae-oncology as the sole personnel to conduct sexual health assessment in pelvic radiotherapy was also reported by participants in a national survey of vaginal dilator use (White & Faithfull, 2006).

The level of knowledge and expertise regarding the assessment and management of female sexual difficulties varied markedly between the four clinical nurse specialists (CNSs) who took part in the study (see section 9.1.2). The gynae-oncology nurse specialists had greater clinical experience and knowledge regarding treatment induced menopause, infertility and the sexual aspects of pelvic dysfunction than those working with women treated for anal or rectal cancer. This low level of specialist nursing expertise regarding women's sexual health in pelvic radiotherapy was consistent with findings from a study by White and Faithfull (2006) who found that only 11% of gynae-oncology nurses and therapy radiographers offered patient information about vaginal dilators within the wider context of sexual adjustment after treatment.

From the findings of this study it would seem that systems of supportive care provision for women receiving pelvic radiotherapy placed excessive reliance on the perceived expertise of individual practitioners (particularly radiotherapy department nurses, therapy radiographers or clinical nurse specialists in gynae-oncology) as opposed to establishing a service level response to the assessment and management of sexual morbidity in cancer units, centres, or across cancer networks.

A focus on the roles, knowledge and skills deficits of individual practitioners as opposed to developing a greater understanding of the restrictions maintained by the dominant culture of health care organisations and medical systems is repeated in nursing and medical literature and research on sexuality in health care practice as reviewed in section 2.4 of this thesis. It is interesting to note that although published studies refer to privacy and time pressures as environmental factors influencing the discussion of sexual concerns in clinical settings (Guthrie, 1999; Cort et al. 2001; Gott et al. 2004a), none of the literature reviewed contains any detailed analysis of the service design and organisational
culture elements that serve to maintain the invisibility of female sexual difficulties following cancer treatment. A recent exception to this omission was a study by Hordern and Street (2007a). This qualitative study was based on the work of Anthony Giddens, who examined the nature of subjectivity in modern society through the study of its structures and actions (Giddens, 1991, 1992). Horden and Street (2007a) explored the degree of reflexivity demonstrated by both patients and health professionals in their personal constructions of sexuality in light of the organisational structures that govern cancer and palliative care settings. These authors explained that:

"Irrespective of the scientific and technological sophistication evident throughout these modern clinical spaces, the patients were firmly located in traditional, less reflexive practices by the health care structures in place. There would never be the time or place to acknowledge patient issues of intimacy or sexuality within these clinical settings where the dominant emphasis remained at the level of cancer treatment and problem-based medicine." (Hordern & Street, 2007a: 12)

The lack of a systematic appraisal of organisational contributors perpetuates the marginalisation of female sexual difficulties as a legitimate clinical problem worthy of resource allocation, staff and service development. The ad hoc approach to service delivery seen in this study inevitably resulted in variable treatment experiences for individual women and couples through the lack of any minimum agreed standard of care or service provision for female sexual difficulties. This service omission was in stark contrast to the management of erectile dysfunction at both cancer centres where there was an established specialist erectile dysfunction (ED) service on site for male patients. This apparent disparity between the clinical profile and management of male and female sexual difficulties within the cancer centres was also evident from analysis of the organisational structures and processes related to the provision of pelvic radiotherapy and the views expressed by some health professionals that women did not appear to place the same importance on their sexual lives as male patients undergoing pelvic cancer treatment (section 9.1.3). As discussed previously, female sexual difficulties arising from radical pelvic radiotherapy were not mentioned in radiotherapy consent documents while impotence (now more commonly referred to as erectile dysfunction) was included as an important late toxicity for male patients in all pelvic radiotherapy consent forms. This suggests a gender disparity in the clinical profile given to male and female sexual morbidity associated with pelvic radiotherapy. Perhaps the higher profile of male sexual dysfunction (mainly ED) arising from the management of pelvic cancer relates to the ready
availability of an effective biomedical intervention. The introduction of sildenafil (Viagra) in the 1990's and subsequent development of two additional drugs, tadalafil (Cialis) and vardenafil (Levitra) has transformed the medical management of male sexual dysfunction in cancer care (Incrocci, 2007a).

Medical staff may be more willing to ask questions about erectile function after cancer treatment if they can offer an immediate pharmacological intervention based on a plethora of biomedical research evidence. This was borne out by findings from a recent unpublished ethnography conducted in two contrasting prostate cancer clinics (one surgical clinic and one radiotherapy clinic). Participant observation of 60 consultations in these London based oncology follow-up clinics revealed an enquiry rate about sexual concerns after prostatectomy of 54% and 52% following radical prostate radiotherapy (Kelly, White & Marshall-Lucette, 2008) compared to a mere 25% enquiry rate for female sexual difficulties in the observation component of this study. Given the relative importance health professionals attributed to the age of women in considering whether or not to enquire about sexual recovery it was interesting to note that the male patients observed in these clinics were considerably older (mean age 70 years, range 50-86 years) than the female patients (37/69 [53.6%] aged >60 years) observed in this study's consultations. These findings, together with the relative paucity of literature regarding the management of female sexual difficulties after pelvic cancer treatment speaks of a gender inequity in both clinical and research arenas (Miles et al. 2007). The lack of a robust evidence base for the management of female sexual dysfunction arising from cancer treatment may in part be based on gendered perceptions regarding the relative importance of sexuality and sexual function to men and women. Nevertheless, the women who took part in this study demonstrated an interest in their sexuality and how cancer services addressed this aspect of their recovery, even when such interest did not always translate into the personal priority women accorded sexual expression within their current relationships.

Given the relatively low clinical and research profile of female sexual difficulties after cancer, what does it mean for women's sexual well-being to be invisible and narrowly defined through the clinical gaze and conduct of the clinic? As Foucault (1973: 142) explains:

“A hearing gaze and a speaking gaze: clinical experience represents a moment of balance between speech and spectacle. A precarious balance, for it rests on a formidable postulate: that all that is visible is expressible and that it is wholly visible because it is wholly expressible.”
Wheatley's (2005:439) ethnographic study of a cardiac rehabilitation clinic drew on Foucault's ideas to explore how the power derived from medical knowledge was made visible through "...medical techniques and practices that constitute bodies as objects of knowledge." Wheatley (2005: 439) also contends that:

"Medical clinical encounters require patients to reveal the secrets of their bodies through verbal confessions and to subject themselves to physical examinations."

But what if physical examinations (vaginal examination) cannot detect some sexual difficulties such as loss of sexual desire or dyspareunia? And what if women in the clinic act as "self-policing subjects", keeping their sexual concerns secret and thus invisible to techniques of medical surveillance? While Foucault (1973) speaks of the clinical gaze as a technique of medical power and method of social control, the failure to see or speak of female sexuality in the clinic serves to exclude female sexual morbidity from legitimate medical (and nursing) discourse. Such exclusion makes appropriate clinical assessment and management of women's sexual concerns less likely within mainstream oncology service provision.

A recurrent theme in sections 11.3 and 11.4 of this chapter is the extent to which medical practice has the power to dictate which treatment side effects and illness experiences are worthy or unworthy of clinical attention. I would further suggest that medical legitimacy is also a key determinant of service provision, particularly in health care systems that have to manage scarce resources. The question that remains is how can other health care professionals and women themselves redress the apparent power imbalance that has led to the relative neglect of female sexual difficulties arising from cancer treatment and in so doing create the philosophical and clinical will to assess and manage women's sexual concerns in the oncology clinic? Or in Foucauldian terms, if it is the relationship between power, knowledge and discourse that shapes health care systems and individual practice therein, how might women and health care professionals co-construct alternative discourses about female sexuality after cancer in offering a resistance to biomedical hegemony (Foucault, 1973; Cheek & Rudge, 1994)?

11.3 Constructions of Female Sexuality after Cancer Treatment
The nature and meaning of female sexuality among women who have been treated for cancer cannot be explored, defined or fully understood in a contextual vacuum. For many women their pre-illness sexuality was reconstructed through the experience of cancer as a life limiting condition and through the relative importance individual women gave their sexual well-being within the context of that existential threat (section 7.1). The centrality of sexual expression to women's well-being and to couple relationships varied substantially among the women and partners interviewed in this study. Although one may have assumed sexuality was a priority in participants' lives because they had all volunteered to take part in this study, eleven women disclosed that they considered their sexuality to be a low priority in the context of their survival from cancer (section 7.1.1), particularly in the first six to 12 months following treatment completion (Hordern & Street, 2007a).

The first challenge for health care professionals in understanding the personal meaning of treatment induced sexual changes is to be able to place these changes within the context of women and couple's diverse relationships and sexual lives prior to the onset of illness. However, as recording even a brief sexual and relationship history pre-treatment was not currently an element of routine medical or nursing assessment, placing the meaning of sexual changes to women in context post-treatment is problematic. The absence of baseline data regarding this aspect of women's lives made post-treatment comparisons difficult and thus the identification of women or couples at greater risk of sexual difficulties post-treatment for the purpose of targeted intervention was impossible.

As discussed in section 11.2, the dominant philosophy and practice of biomedicine shapes how a complex abstract phenomenon such as sexuality is boundaried, interpreted and managed within any given health care system (Hordern & Street, 2007a). Furthermore, when human sexuality is viewed through the lens of serious illness it is perhaps unsurprising that it undergoes a transformation or reconstruction. This transformation is shaped by belief systems about cancer and female sexuality operating at an individual, organisational and societal level. Such belief systems determine how sexuality may be viewed in the context of cancer treatment from the perspectives of women, their partners and health professionals. The findings of this study suggest that the social construction of female sexuality within the oncology follow-up clinic is essentialist, heteronormative and that satisfactory female sexual function is defined predominantly as the receptive capacity of the woman's vagina to accommodate penile penetration without stenosis or pain (Hyde, 2007). This particular construction of women's sexuality after cancer emanates from health professionals but is endorsed by the majority of women and
partners who participated in this study. Hyde (2007) contends that through the lens of biomedicine, "normal" or "healthy" female sexuality has been constructed as passive and receptive in response to a more active phallocentric male sexuality as opposed to being considered an active or engaged force in and of itself. This construction of female sexuality in narrow genital and functional terms may explain why, as discussed in section 11.2, the assessment of post-treatment sexual function in the clinic was normally restricted to evaluation of the integrity and patency of the vagina, limited discussion of treatment induced menopause and a somewhat brief and infrequent enquiry about whether or not sexual intercourse had been resumed. These findings are consistent with the construction of female sexuality reported in the biomedical literature reviewed in sections 2.5 to 2.7 of this thesis. It appears that in both clinical and research contexts, the resumption of sexual intercourse by women after cancer treatment is seen to represent satisfactory sexual recovery. As will be discussed later in this chapter, the majority of women in this study did resume penetrative sexual intercourse following cancer therapy but still experienced a number of detrimental changes to their sexual satisfaction including loss of sexual interest, dyspareunia and reduced orgasmic sensation. These findings suggest that clinical evaluation of satisfactory sexual adjustment after pelvic cancer therapy should not rely predominantly on the resumption of sexual intercourse as its outcome measure as women are motivated to engage in sexual intercourse by a variety of personal and relationship factors (Van De Wiel et al. 1988; Andersen & Van Der Does, 1994; Andersen et al. 1997). Engaging sexually with a partner in the absence of a strong personal desire for sexual contact is not unique to women with low desire after cancer treatment. Many women in long-term marriages or intimate relationships try to increase their motivation to be sexual in order to sustain harmony within their relationship, particularly where the male partner is experienced as having a greater desire or drive to be sexual (Elliott & Umberson, 2008).

During medical follow-up, health professionals in this study did not routinely enquire about the psychological, relational or broader behavioural aspects of women's sexuality. In study interviews women readily discussed the relationship context for their sexual recovery together with what may be considered more subjective and less "functional" aspects of sexual expression such as sexual desire, arousal, orgasm and sexual satisfaction (sections 8.4, 8.5, 8.7). As explored in sections 2.5 and 2.6 of this thesis, the biomedical literature that most medical, nursing and radiographer staff rely upon fails to explore female sexuality after cancer treatment in its interpersonal or socio-cultural contexts (Vistad, Fossa & Dahl, 2006). Over reliance on and uncritical acceptance
of this particular evidence base has inevitably led to a neglect of elements that support a more diverse and holistic view of female sexuality in favour of this functionalist, phallocentric sexual norm that now dominates both clinical and research practice in oncology (Hyde, 2007). Hence in contrast to much of the rhetoric about holistic sexuality referred to in the nursing literature (Thaler-DeMers, 2001) the more diverse and active aspects of women's sexual expression do not appear to define female sexual function within the reality of cancer care.

This somewhat narrow construction of female sexuality manifests itself in the clinic through a low level of enquiry about women's sexual desire and the complete omission of questions about female orgasm or sexual satisfaction (sections 8.5 and 8.7). When aspects of sexual desire or arousal were addressed within the clinic this was always within a biomedical frame of reference, with an emphasis on limited physiological and hormonal parameters or markers of disruption to these phases of the human sexual response (Hyde, 2007). On the few occasions where loss of sexual desire was discussed in the clinic (n = 7 / 30 observed consultations with women who had treatment induced ovarian failure) this was normally in relation to the provision of hormone replacement therapy (HRT) for women experiencing a medically induced menopause as opposed to exploration of women's sexual desire in any wider personal or relationship context. Fourteen of the 24 women interviewed for this study commented upon temporary or persistent loss of desire for sex. Some women attributed this change to treatment induced menopause, while others felt their lack of interest was due to fear of pain, fear that sex could cause their cancer to return or due to altered femininity or sexual identity (Lamb & Sheldon, 1994; Juraskova et al. 2003).

Sexual arousal was not directly enquired about in either subjective or objective terms and the presence of vaginal dryness, a symptom commonly associated with altered sexual arousal patterns in women, was defined purely as a vaginal change induced by surgical and radiotherapy treatment for pelvic malignancy.

The presence of sexual pain as a consequence of treatment induced menopause, vaginal dryness and increased fragility of the vaginal and vulval mucosa was also rarely asked about (n = 4 / 69 consultations) by health professionals and in observed consultations was never raised by women in the clinic. This was despite the fact that during study interviews, six women spoke of experiencing temporary dyspareunia while a further four had endured persistent dyspareunia that continued to cause them distress and
adversely affect their sexual lives and that of their partners (section 8.6). When sexual pain was raised in the clinic by one of the women interviewed for this study there was further evidence of a narrow biomedical or anatomical lens being used to evaluate this symptom. This woman (PT19) felt that her consultant (HCP02) had assumed that if her vagina was deemed adequate by vaginal examination to accommodate an erect penis, then her complaint of vaginal pain was invalid from his perspective. The interpretation of this woman’s sexual pain had been considered solely in anatomical terms at the expense of encouraging this woman to reveal more of her experience and perhaps considering broader functional or psychogenic origins for her pain (Hyde, 2007). The increased prevalence of dyspareunia following pelvic cancer treatment found in this study is supported by published literature, with sexual pain encountered more frequently in women who have received pelvic cancer treatment than in the general female population (Schover et al. 1989; Jensen et al. 2003). The prevalence of sexual pain among women in this study suggests that assessment of the presence and nature of sexual pain may be a useful component of routine post-treatment sexual morbidity assessment.

As mentioned previously, changes in orgasmic sensation and capacity were never discussed with the women who took part in this study, despite eight of the 24 women readily disclosing orgasmic changes (decreased intensity, less satisfying, delayed or more difficult to achieve) as a result of direct questioning in study interviews. One explanation for the omission of detailed questioning about specific aspects of women’s sexual recovery after cancer treatment is that such topics are considered too intrusive by health care professionals and avoided out of concern that women would be embarrassed by such questions (Gott et al. 2004a; Burd et al. 2006). However, in an earlier study of women treated for ovarian cancer, Stead et al. (2001) found that although women acknowledged they may experience some embarrassment, they felt that the personal benefits of learning more about altered sexuality after cancer would outweigh any discomfort they experienced in discussing sexual issues with health care professionals.

I acknowledge that the women taking part in this study were a self-selected group who may have been more willing to answer questions about their sexual lives after cancer. Certainly I did not find more than a mild reticence to engage in sexually explicit discussions and once a rapport had been established we talked, often in considerable detail, about their relationships and sexual expression both before and after their cancer experience. As discussed previously in section 3.5.1, the recorded interview transcripts in
this study represented only a proportion of the time spent with participants in discussion of their personal circumstances, relationship and illness context for their sexual adjustment after treatment.

Data from women's interviews confirmed that all phases of women's sexual response cycle could be affected by cancer therapy to varying degrees. Six of the 24 women interviewed perceived that there had been no lasting change in their sexual relationship post-treatment. This was particularly the case where sexual expression was infrequent or was perceived to be a less important aspect of the couple's relationship. Nineteen of the 24 women interviewed were sexually active with a partner immediately prior to their cancer diagnosis, of which 15 had attempted sexual intercourse post-treatment. Of the 15 women who had attempted sexual intercourse in the weeks and months following treatment completion, 13 were still sexually active while two had not tried to have intercourse again, one because of pain and the other due to fear of vaginal bleeding. Five women who had been sexually active before their treatment had not attempted to engage in sexual intercourse since their treatment and this had led to a complete cessation of any sexual contact for the couples. Two of these women had developed severe vaginal stenosis that made even dilator use difficult and three women had a complete loss of sexual desire and were fearful of resuming sexual contact with their partner (section 8.4 and 8.8).

The prevalence and nature of vaginal changes and sexual difficulties including vaginal dryness, vaginal stenosis or shortening, dyspareunia and low sexual desire experienced by the majority of women (18 / 24) interviewed for this study were commensurate with findings from published biomedical studies reviewed in sections 2.5 and 2.6 of this thesis. Published studies confirm a relatively high prevalence (50-80%) of sexual difficulties among women who have completed pelvic radiotherapy for cervical cancer (Crowther et al. 1994; Flay & Matthews, 1995) with the most common difficulties reported as being decreased sexual desire, decreased frequency of sexual intercourse, vaginal dryness, stenosis and shortening and dyspareunia (Marijnen et al. 2005; Vistad, Fossa & Dahl, 2006).

In addition to the sexual disruption caused by physical late effects manifest in the vagina or pelvis, a number of women (15 / 24 women) also spoke of the fear they experienced in contemplating the resumption of sexual intercourse after treatment was completed. This fear appeared to be related to concerns about experiencing sexual pain for some women while for others it was associated with pervasive myths about radiation
contamination or the reactivation of cancer through sexual activity. The low level of discussion about sexual concerns in the clinic setting meant that these women had not been offered any opportunity to explore their fears or sexual reality with a health professional (Robinson, Farris & Scott, 1999).

Six women specifically referred to the impact of altered appearance and function on their sense of femininity and sexual identity after cancer treatment. The four women who had been given a temporary or permanent colostomy as a consequence of treatment for rectal cancer were the most commonly affected (Manderson, 2005). However, others who experienced loss of pubic hair, severe tissue changes in the perineal region, or who had developed reduced control over bladder or bowel function also experienced a loss in femininity and a reluctance to resume sexual intimacy with their partners (Juraskova et al. 2003). Sexual identity and associated sexual confidence was also adversely affected by the proximity of the women's cancer site to parts of their body normally associated with sexual activity, and the fear of experiencing post-coital bleeding that women associated with either internal damage caused by sexual activity or a recurrence of their illness (Butler et al. 1998). The impact of pelvic malignancy and associated treatments on the sexual identity and femininity of women was not addressed in the medical and nursing discussions observed in the clinic, nor were such discussions prevalent in the narratives of women and partners interviewed for this study. Many of the women commented that taking part in the study interviews had been the first opportunity they had had to fully explore the meaning of sexual changes that had taken place and to disclose the emotional impact of such changes on them and their partners (Hordern & Street, 2007b).

Fear of resuming sexual intercourse, loss of femininity, orgasmic changes and reduced sexual satisfaction for the woman and her partner were infrequently reported in the literature, although were more likely to be found in studies that had adopted a qualitative method such as in-depth interviews (Lamb & Sheldon, 1994; Butler et al. 1998; Juraskova et al. 2003) as opposed to those using validated sexual function or QOL postal questionnaire surveys.

This study also confirmed findings prevalent in published literature regarding the ageist assumptions made about older women's sexuality (Haboubi & Lincoln, 2003; Gott et al. 2004a; Burd et al. 2006). Sixteen out of the 20 health professionals interviewed believed that older women would either not consider their sexual lives important or were unlikely to be sexually active. This was in stark contrast to eight women over the age of 60
years who took part in interviews and expressed interest in continuing their sexual lives as long as their recovery and health permitted.

11.3.1 Heteronormativity and the paradox of the invisible man

Scrutiny of the medical literature revealed study exclusion of women who were not in a current sexual relationship (Juraskova et al. 2003) or who had not had recent sexual intercourse (section 2.7). All of the single women who were interviewed for this study (PT01, 03, 04, 08, 17) expressed gratitude that they had been invited to participate as this signalled to them that they were considered to have sexual potential despite their cancer diagnosis and single status. Four of these women had remained sexually active through self-stimulation and all expressed an interest in pursuing a new relationship in the future. The exclusion of women who are not in a current heterosexual relationship from studies about sexual adjustment after cancer serves to further define female sexuality in narrow heterosexist terms and means that we learn very little about the sexual recovery of women in same sex partnerships or those not in a current relationship but who may be sexually active through masturbation or other forms of sensual self-expression (Hyde, 2007).

Studies that have explored the nature of how couples adapt to and cope with the stressors associated with cancer and other types of chronic illness have increased significantly in recent years (Berg & Upchurch, 2007; Hagedoorn et al. 2008). Despite only a moderate association between patient and partner distress in the face of cancer, there is sufficient research evidence to suggest that couples often respond to the stress of cancer diagnosis and treatment as an emotional system as opposed to solely as an individual (Van de Wiel, Weijmar Schultz & Thurkow, 1991; Hagedoorn et al. 2008). While the partner appears to influence the adjustment of the patient, the emotional well-being of the partner is also affected by the diagnosis of cancer and its treatment (Hagedoorn et al. 2008).

In keeping with the narrow biomedical frame of reference used to construct female sexuality within the clinic, interpersonal aspects of women's sexual relationships were not explored and thus partners were normally absent from the infrequent discussion of sexual concerns in the clinic. Nine out of 20 health professionals interviewed felt that the presence of women's partners in health care consultations acted as a barrier to the open discussion of sexual issues in contrast to only one woman (PT11) and one partner (PTNR03, married to PT07) who specifically felt that the presence of a partner could inhibit such discussions. The reasons given by health professionals for this belief was either that
the presence of a male partner would influence the honest appraisal of sexual recovery by
the woman or that they felt inhibited speaking to the woman with her male partner present
(sections 6.6 and 9.1.1). This apparent reticence to engage the partners of women with
sexual concerns when discussing treatment induced sexual difficulties found in this study
is not reported in any of the literature reviewed in chapter two.

Much of the literature focused on couple adjustment in the context of long-term
illness suggests that the psychosocial adjustment of the person who is ill is enhanced
where the male partner is experienced by the woman as being supportive and
collaborative as opposed to either over-protective or emotionally disengaged (Berg &
Upchurch, 2007). The majority of women interviewed in this study identified their partners
as an important source of social and emotional support and a key contributor to their
sexual recovery (section 7.2.1). However, the absence of partners from clinical
discussions about sexual concerns, together with a consistent failure to enquire about the
woman’s relationship context, meant that the impact of cancer treatment on a woman’s
intimate and sexual relationship was rarely known or documented in the clinic. As can be
seen from section 2.5.1, there are relatively few studies that have specifically explored the
sexual consequences of cancer for couples where the woman has been treated for a
pelvic malignancy. When illness and treatment has a high impact on the meaning and
function of the couple relationship then shared appraisal of the threat posed by cancer and
couple coping strategies may be adversely affected. Altered sexuality and sexual
expression may lead to decreased sexual and emotional intimacy at a time when the
couple need greater intimacy in order to “buffer” the impact of illness on their emotional
adjustment (Scott, Halford & Ward, 2004; Berg & Upchurch, 2007). In this study (Scott,
Halford & Ward, 2004) the relationships that women reported as being strong and
supportive became emotionally closer under the threat to survival posed by cancer, whereas
those relationships where withdrawal or conflict was a feature were experienced
by women as emotionally distant and unsupportive (see sections 7.2.2 and 7.2.3).

Of the five women who were not partnered at the time of their study involvement,
two women (PT01 and PT04) had experienced relationship breakdown as a direct result of
the additional stressors created by the diagnosis and treatment of their cancer (section
7.2.3). In both instances there had been considerable relationship conflict prior to the
woman’s illness and both women had experienced poor or absent spousal support during
their cancer treatment (Berg & Upchurch, 2007).
Although only a small number of male partners agreed to take part in this study (five out of the fifteen men approached) they offered important insights regarding their fears and concerns as they recalled their efforts to support their partners during and after cancer treatment. Some of the men referred to concerns they held about causing pain or internal damage to their partner through resumption of sexual intercourse and spoke of a need to proceed with caution when attempting intercourse in the early weeks or months post-treatment (sections 8.6 and 8.8).

Of the five men interviewed only two had been able to both resume and maintain sexual intercourse with their partner. One couple had tried to resume intercourse but persistent dyspareunia had led them to cease all sexual contact, while another couple had not been able to resume penetrative intercourse due to severe vaginal stenosis. In both cases these men (PTNR03 and 04) had stopped other forms of sexual intimacy with their partners because they found it too emotionally difficult for both themselves and their partners to create sexual intimacy and arousal without the ability to experience subsequent sexual satisfaction through penetrative sex. Both these couples expressed regret at the loss of sexual intimacy in their relationship resulting from cancer treatment and the women expressed regret in no longer being able to provide a suitable outlet for their partner's sexual needs.

Only one of the men interviewed (PTNR05) readily accepted the loss of sexual intercourse from his relationship as he felt his level of sexual desire had never been particularly high. He and his partner (PT21) were content with the emotional closeness and affection still possible within their relationship as intercourse had never been an important aspect of their relationship prior to his partner's illness.

Although a number of women felt their ability to be sexually active was not important to them personally, they wanted to be able to do so in order to meet the perceived sexual needs of their male partner and to maintain the intimacy within their relationship. This is an important finding to acknowledge, particularly when interpreting female sexuality from a feminist or socio-political perspective. While it may be theoretically important to recognise the gender politics that shape the ways in which biomedicine and conventional sexology frame female sexuality in heterosexist and phallocentric terms, the reality for the majority of these women is that they are currently in, or aspire to engage in, heterosexual relationships where it remains important for them to be able to offer vaginal sex (Van de Wiel et al. 1988). Authors such as Hyde (2007) rightly offer a critique of the narrow bias in
medical and sexological literature towards penetrative vaginal intercourse as the dominant rehabilitation goal for women whose sexual lives have been adversely affected by cancer treatment. However, she offers no realistic alternative for women and partners who prefer this mode of sexual expression to non-coital forms of sexual expression. In this study "sex" was equated with "sexual intercourse" by all groups of participants and intercourse was the dominant form of sexual expression referred to by both the women and their partners. Non-coital forms of sexual expression were alluded to within women's transcripts (section 8.5) but were not viewed as an equal alternative to penetrative vaginal intercourse. A number of the women alluded to the importance of being able to be sexual for the sake of fulfilling their partner's need for sexual outlet regardless of their own levels of sexual interest or enjoyment (sections 7.3, 8.7 and 8.8).

Some feminist writers such as Hyde (2007) tend to frame male partners of women with cancer in a somewhat negative light, implying that the majority of women may find themselves engaging in painful sexual intercourse as a consequence of the gendered oppression inherent to heterosexual relationships. This viewpoint is an important limitation of feminist analyses of sexuality and gender, particularly as the more radical feminist perspective fails to offer any realistic alternative for those women and men who wish to continue their preferred forms of sexual expression as a couple.

While there was one clear case of male partner coercion in this study (PT13), a more common finding was the extent to which women felt that their sexual fears were understood and accommodated by their partners. Far from being inconsiderate men who believed in fulfilling their "sexual rights" at any cost, all of the men who were interviewed and many of the partners mentioned by women in this study considered the comfort and survival of their intimate partner of paramount importance (section 8.8).

In summary, the construction of women's sexuality in this study was consistent with that encountered in the biomedical literature reviewed in sections 2.5 and 2.6 of this thesis. Female sexuality was defined in narrow biomedical terms and health professionals excluded the subjective elements of women's sexual expression (desire, arousal, orgasm and satisfaction) from infrequent clinical assessment in favour of a functional genital definition where vaginal patency and frequency of sexual intercourse equated with satisfactory sexual recovery. Sexuality was also seen by health professionals as being more important to younger women, particularly those who were pre-menopausal. In keeping with a somewhat narrow biomedical perspective, relationship contributors to
women's sexual adjustment and the impact of sexual disruption on the woman's partner were not normally explored in practice.

11.4 "Talking Sex" in the Clinic

Medical follow-up clinics were experienced by the majority of health professionals and women as an inappropriate environment for the conduct of sensitive and time consuming discussions about women's sexual recovery after cancer treatment (Stead et al. 2001; Gott et al. 2004b). As discussed in chapter nine, and in keeping with findings from published studies reviewed in chapter two, there were a large number of factors identified by health professionals, women and their partners that inhibited communication about sexual issues in the clinical setting. A wide range of communication barriers emanating from the clinic environment, patient and health professional's personal characteristics adversely affected participants' confidence and willingness to talk about treatment induced sexual difficulties in practice.

Health professionals were self-conscious about the presence of others in the consultation room and this decreased the likelihood that questions about women's sexual concerns would be asked, despite this having no apparent influence on the level of enquiry about other private bodily functions such as bladder and bowel function. Self-censoring behaviour that emanates from awareness of the gaze of others is a recurring them within a number of Foucault's works, including The Birth of the Clinic (1973), Discipline and Punish (1977) and the History of Sexuality Vols 1-3 (1990a, 1990b, 1992). From a Foucauldian perspective, Cheek and Rudge (1994:587) suggest that "powerful groups of experts" within hospitals (predominantly doctors but can incorporate other health care professionals) determine what constitutes normality on the basis of their claims to specialist professional knowledge. The bounds of normality are policed by "professional experts" through surveillance activities that include physical examination, recording vital signs or enquiring about particular lifestyle choices or behaviours and through these mechanisms the "docile body" is produced. This description refers to the mechanisms by which patients are classified and become controlled by health care systems. However, health professionals also become self-censoring in their clinical practice as they respond to the processes of surveillance inherent to medical and nursing systems, such as being observed in the clinical environment by supervisors, colleagues (section 9.1.1) or by patients themselves.
Through mutual surveillance a "normalisation" process is enacted that maintains the status quo and determines which topics are deemed to be worthy of medical time and those that fall outside that norm (Cheek & Rudge, 1994).

Evidence of self-censoring behaviour was also present in the women's accounts of their experience of the clinic as they learned about which aspects of their illness experience were deemed legitimate medical topics that could be raised with their treatment team and which aspects of their sexual recovery were inappropriate to discuss or were not defined as "medical problems" (section 9.1.2). Women appeared to reach conclusions about the relevance of certain aspects of their post-treatment recovery to their medical team through the infrequency with which certain topics, such as sexual well-being, were discussed in the follow-up clinic. They made assumptions based on comparisons of the level of written and verbal patient information about different treatment side effects made available to them across their treatment journey (Hordern & Street 2007a; Hordern & Street 2007b). As discussed in section 6.3, a number of women lamented the paucity of information available to them regarding sexual difficulties associated with their radiotherapy compared to the level of health practitioner discussion about bowel and bladder toxicities (Hordern & Street, 2007a; Faithfull & White, 2008).

The influence of perceived time pressures in the clinic setting was evident in the interview transcripts of both health professionals and women as both groups struggled to achieve acknowledged assessment priorities within individual and organisational constraints. Sexual concerns were recognised by both groups of participants as a sensitive topic that was likely to require more time to discuss than other treatment impacts (Stead et al. 2001) and this perception meant that when the time available was considered inadequate, prioritisation by medical staff led to sexual concerns being omitted when clinics were busy and there was a risk of creating further delay within the system (Gott et al. 2004b).

A factor that may also have influenced topic prioritisation in the clinic was the belief expressed by eleven of the 24 women interviewed in this study and five out of the eleven doctors who took part, that they did not consider the discussion of treatment induced sexual morbidity part of the oncologist’s role. Women who expressed this view felt that the principle role of their medical specialist was to ensure their survival through disease monitoring and that their sexual recovery was relatively unimportant until their survival was assured. Patients' expectations of the role of their medical specialist in addressing illness or treatment related sexual problems with them were discussed in a study by Sardaki and
Rosenqvist (2001). In their study of women who attended their GP for diabetes management, patients could not perceive their doctor in the role of “sexual counsellor” when they played a key role in helping them to manage the medical aspects of their illness. These findings are also supported by data from a more recent Australian study in oncology (Hordern & Street, 2007a) among a sub-group of patients who placed their doctor in the role of the ‘traditional expert’. These patients expressed a belief that their survival was more important than the sexual consequences of their treatment and that if their doctor deemed this topic to be important enough to discuss, they would address sexuality concerns with them. The findings of this current study and more recent studies cited in this chapter contradict the earlier findings of Waterhouse’s (1993) study that found 66% of a sample of healthy volunteers felt that doctors should ‘always or almost always’ discuss sexual concerns with their patients. These differences in findings may well represent the influence of people’s direct experience of significant illness upon their views about the realistic priorities of their doctors within the resource constraints of modern British healthcare systems.

Women, partners and health professionals all considered the discussion of sexual concerns challenging and potentially embarrassing (Lawler, 1991; Meerabeau, 1999; Cort et al. 2001). Commensurate with findings from published research (Gott et al. 2004a; Gott et al. 2004b; Burd et al. 2006), the patient characteristics considered most likely to be associated with patient and thus health professional embarrassment in this study were if the woman was older (over 60-70 years of age), from an ethnic minority community or held strong religious convictions (particularly those following Islam or Judaism). Women with these characteristics were assumed to be more reticent to talk openly about sexual concerns due to embarrassment associated with holding more “traditional” attitudes towards sexual expression.

Health professional characteristics that appeared to inhibit staff asking questions about sexual difficulties after cancer treatment mainly related to a personal belief that they lacked the specialist knowledge or expertise regarding the management of problems that might be elicited from women (Merrill et al. 1990; Cort et al. 2001; Haboubi & Lincoln, 2003). Most published studies have focused on the knowledge deficits of individual practitioners as the dominant explanation for low levels of clinical enquiry about patient’s sexual recovery after cancer or chronic illness (Matocha & Waterhouse, 1993; Cort et al. 2001; Haboubi & Lincoln, 2003).
In this study all health professionals spoke of the paucity of sexuality education available locally to improve their knowledge and skills both in relation to the conduct of sexual health assessments and the clinical management of women's sexual difficulties after cancer treatment (section 9.1.2). Nurses had accessed some in-service training or brief educational input related to sexuality but still felt there was inadequate provision of specialist education on this particular topic in their clinical setting. None of the medical staff interviewed had undertaken any formal training in sexuality. Furthermore, doctors appeared to rely on role modelling to develop this aspect of their practice because of the paucity of published literature on the assessment and management of female sexual dysfunction. Given the low prevalence of clinical discussions about sexual morbidity associated with pelvic cancer treatment in this study it is unlikely that reliance on role modelling from colleagues would lead to any substantial improvement in current medical practice. In a study of marital and family therapists (Harris & Hays, 2008) researchers found that increased clinical exposure to sexuality discussions alone was unlikely to improve therapist's perception of either their knowledge base or to increase their comfort in initiating discussions about sexuality, especially if clinical experiences had been negative or undertaken reluctantly.

In exploring practitioner knowledge base, participants expressed greater confidence addressing the biomedical interventions that were within their remit to offer to women experiencing sexual difficulties, such as prescribing hormone replacement therapy (HRT), lubricating creams / gels or providing vaginal dilators (Hordern & Street, 2007a). However, as discussed previously, knowledge and practitioner confidence regarding the emotional and relationship elements of women's sexuality were not evident among the health professionals interviewed and couple management skills were not a consistent element of the majority of practitioner's armoury of clinical tools.

In published literature and within clinical practice there appears to be a somewhat uncritical belief that simply by increasing health professional's knowledge regarding sexual difficulties there will be improvements in the clinical assessment and management of patients' sexual concerns. However, as discussed in section 2.4, there remains a complex and ill-explored relationship between the specialist knowledge held by health professionals, personal attitudes towards sexuality, practitioner comfort or confidence regarding discussion of sexual difficulties and the skills necessary to effect change in actual clinical behaviour (Lewis & Bor, 1994; Waterhouse, 1996; Rosen et al. 2006;
Tsimtsiou et al. 2006). More recent studies have placed greater emphasis on the positive influence of communication skills training in promoting the discussion of sexual issues with patients (Tsimtsiou et al, 2006). Other contributory factors included the practitioner's area of speciality (urologists, gynaecologists and psychiatrists conduct sexual assessments more frequently) and health professionals who were interested in patient's psychosocial concern were also more likely to enquire about sexual well-being (Tsimtsiou et al. 2006).

A recent study by Harris and Hays (2008) supported an earlier assertion made by Waterhouse (1996) that the acquisition of formal specialist knowledge needs to be supported by appropriate clinical experience and professional supervision. It is this combination of strategies that is more likely to promote the critical development of professional comfort and skill in addressing the sexual concerns of patients / clients.

Even in Harris and Hay's (2008) study of marriage and family therapists, practitioners felt ill-prepared to discuss sexual issues with clients and knowledge alone did not equip therapists to effect practice change in this respect (Harris & Hays, 2008). The study found that practitioner's sexual education and supervision experiences had most influence on therapist's comfort in discussing sexual issues with clients. Increased comfort with the sexual content of discussions was more important than practitioner's perceived knowledge about sexuality as a precursor for initiating discussions about sexuality with clients (Harris & Hays, 2008).

Relatively few studies have adequately explored the organisational culture and service resource elements (with the exception of environmental privacy and time constraints) that influence health professionals in their decision whether or not to ask patients about their sexual concerns (Guthrie, 1999; Haboubi & Lincoln, 2003). In this study health professionals stated they were inhibited from asking women about their sexual recovery by the absence of standard / clear referral pathways or management policies to guide the assessment and management of what was viewed as a complex and sensitive aspect of women's recovery. Sexual difficulties were considered time consuming to address in the clinic in part because of the absence of any systematic approach to the assessment or management of female sexual difficulties within the cancer centre. There were no care pathways or protocols to determine standard referral systems, to direct inexperienced staff or to ensure that key patient information and provision of biomedical interventions (HRT, vaginal dilators, and advice regarding intimate lubricants) were
available to all women post-pelvic radiotherapy, irrespective of individual practitioner knowledge or awareness (section 9.1.1).

In contrast to the clinical assessment and management of other radiotherapy induced side effects, treatment induced female sexual morbidity appeared to raise health professional's awareness of both a lack of personal expertise and a paucity of specialist knowledge and services available within the cancer centre. Furthermore, the absence of clinical management strategies, policies and clearly identifiable specialist personnel or resources for the management of female sexual dysfunction within the cancer centre could be viewed as an organisational or service deficit that served to undermine the practice of individual health professionals (sections 9.1.1 and 10.4). This finding does not appear to have been explored in published research to date.

There were relatively few factors identified by participants that were considered to be enablers of sexual talk in the clinic, but the ability to create a good rapport in the professional-patient relationship was singled out by women as the most important determinant of successful discussions about their sexual concerns. Women also commented on the importance of continuity of personnel, finding it easier to talk to health professionals about sensitive issues when they felt the practitioner knew them and something of their personal circumstances. In this study women referred to the nature of this supportive relationship as one that enabled the development of "rapport". The characteristics of this concept appear to relate closely to what is referred to in the nursing literature as intimacy (Williams, 2001). William's (2001:192) small qualitative study of nurse's experiences of intimacy within the nurse-patient relationship referred to the nature of intimacy as:

"...disclosure related to deeply personal information. Information shared was highly intimate and would not be shared with others. A suitable person would be carefully chosen with whom to share what appeared to be deeply held secrets often relating to the patient's private life."

As identified by some of the women in this study from their receipt of perineal skin care (section 10.3), the nurses in William's (2001) research conveyed receptivity and "emotional closeness" through the use of physical presence or touch, particularly in the provision of care where cultural norms were breached in the handling of parts of the body normally considered private except between "intimates". Without being explicit about specific nursing or medical behaviours that constituted "rapport", women in the current study
appeared to recognise something in their exchanges with certain practitioners that
corroded being “cared for” or “cared about” even in the conduct of routine examinations
(see HCP02, section 7.4.1) or technical tasks (Allan and Barber, 2005). Conversely, a
number of examples were also given from the same practice contexts (see PT03 and
PT11, section 9.1.2) where a lack of sensitivity to women’s personal circumstances, or an
absence of rapport, had resulted in women withholding sexual concerns they had intended
to express and undermined their confidence in the professionalism of certain practitioners.

The ability to create rapport within the professional-patient relationship was an
important factor in reducing embarrassment experienced by health professionals, patients
and partners when attempting to discuss sexual concerns in the clinic. A factor that was
considered a contributor to improved rapport between a significant minority of women and
health professionals was the ability to have same gender consultations about sexual
matters (Sardaki & Rosenqvist, 2001; Gott et al. 2004b; Burd et al. 2006). However, the
majority of women reiterated that the gender of the practitioner was less important where
the practitioner was a skilled communicator and had the capacity to create rapport in the
clinical exchange. This finding is also supported by a recent study that explored the
influence of gender on physician’s communication style and women’s satisfaction with
gynaecological outpatient consultations (Christen et al. 2008). Patients were more satisfied
with the doctor-patient relationship and consultation process when their gynaecologist was
female. However, this preference was not independently related to physician gender but to
gender-related communication skills, particularly a patient-centred communication style. In
other words, where male physicians used this preferred style of communication they were
also perceived positively by female patients (Christen et al. 2008). The ability of health
professionals to use a patient-centred communication style that incorporates partnership
building and promotes a therapeutic alliance may be yet another example of the nature
and importance of what women in this study referred to as “rapport” in the patient-
professional relationship.

A number of health professionals interviewed in this study had developed personal
strategies to reduce their embarrassment and enhance their communication about sexual
issues. This included the judicious use of humour (Meerabeau, 1999; Hordern & Street,
2007a), depersonalising or normalising the topic of sexual function so it was treated as just
another side effect of treatment (Lawler, 1991) and linking the issue of sexual recovery to
biomedical topics such as the discussion of menopause, vaginal toxicity or vaginal dilator
use (Hordern & Street, 2007a). Health professionals also adopted the strategy of placing this topic towards the end of the consultation once the pattern of communication had been established and was flowing more readily (rapport) between the patient and her doctor (Weijts et al. 1993). However, while distancing or de-personalising communication strategies can make the discussion of sexual concerns more comfortable for the health care professional (Lawler, 1991; Weijts et al, 1993), they may run counter to the wishes of patients who want a practitioner that can create rapport and place discussion of their sexual concerns in a more individual and personal context (Gott & Hinchliff, 2003; Hordern & Street, 2007a).

Women and partners could not agree on the optimal placement of sexual health assessment and patient information within the context of treatment delivery and follow-up and often offered competing rationales as to their individual preference for the timing and delivery mode of such information (section 10.2). The timing of discussions about sexual consequences of treatment across individual women’s treatment journey was experienced by health professionals as inherently problematic. In reality there was a potential tension between the health professional’s proposals to standardise care through development of specific protocols in order to reduce care omissions and some women’s stated preference for a more individualised or responsive approach to their sexual recovery post-treatment. Women suggested that the topic of sexual recovery needed to be addressed at several points during their treatment journey in order to increase the likelihood that women would receive specialist information at a time more relevant to their individual rates of recovery and personal circumstances (Hordern & Street 2007b). As the use of a repeating strategy was adopted by medical staff in their assessment of other pelvic radiotherapy treatment late effects (bowel and bladder dysfunction) it may be that such a routinised approach would also have the desired effect of increasing the clinical profile of female sexual morbidity associated with pelvic radiotherapy. Routine enquiry about the sexual consequences of treatment may be more likely to be achieved if it is systematically embedded into practices that are at the core of follow-up processes.

11.4.1 Re-constructing women’s sexual recovery in cancer care

The findings of this study suggest that it is unlikely that improvement in the assessment and management of female sexual difficulties will be achieved unless some of the
identified communication and practice barriers are addressed through a combination of organisational and individual practitioner development strategies.

Health professionals and women who took part in the study offered a number of suggestions that they felt would improve the current inadequacies regarding the clinical assessment and management of female sexual difficulties after pelvic radiotherapy. Although some of the suggestions appeared to emanate from individual women's experiences that may have been atypical, a number of suggestions achieved a consensus from the majority of both women and health care professionals.

Health professionals and women agreed that the routine delivery of information about sexual difficulties associated with pelvic radiotherapy would be more likely if sexual morbidity and vaginal changes were more comprehensively included in structured treatment consent forms (section 10.4). This would reduce the likelihood that health professionals could avoid the subject of treatment induced sexual morbidity altogether and may have a positive influence, through repeated practice, in shaping individual practitioner communication strategies. Women also made suggestions for improvement in the scope and detail on female sexual difficulties to be found in written patient education materials provided to women at treatment consent and during their attendance at the cancer centre (Faithfull & White, 2008).

In a recent study of pelvic morbidity after radiotherapy (Vistad et al. 2008) comparisons were made between the levels of physician-assessed versus patient-assessed symptoms among women treated for locally advanced cervical cancer five years previously. The findings of this study demonstrated a consistent tendency for physicians to under report the severity of patients' symptoms, with 10% of women rated by physicians as having grade three to four bladder, intestinal or vaginal morbidity compared to 58% of women self-rating severe symptoms from those same organs. This apparent disparity in the rating of symptom severity may relate to the fact that clinicians infrequently record what they consider to be mild levels of radiotherapy morbidity in patient's medical records. In contrast, a woman may experience persistent mild symptoms as more disruptive to her daily quality of life than a single episode of severe toxicity that is subsequently resolved through medical intervention (Vistad et al. 2008).

Vistad et al.'s (2008) findings suggest it may be important to actively pursue women's opinions about the meaning and personal significance of the symptoms they are experiencing, particularly in the assessment of symptom domains that are private, highly personal and difficult to quantify or rate in terms of severity. In this study both health
professionals and women suggested the implementation of structured patient-administered questionnaires that women could complete while waiting for their follow-up consultation to take place. These questionnaires would then be used to guide the medical consultation, making it more patient-centred and responsive to women's priority concerns in its content and conduct (Velikova et al. 2002 & 2008).

Health professional opinion was split as to whether or not such a questionnaire should solely address sexual morbidity, vaginal toxicity and emotional or psychosocial care as elements most likely to be neglected within the current system of follow-up, or to have a questionnaire that addressed all core follow-up topics in an integrated manner (Velikova et al. 2008).

Despite the fact that one of the key aims of this study was to create a clinical assessment strategy that could be used in routine follow-up to improve the assessment of female sexual morbidity in the clinical oncology clinic, determining the specific content of such an assessment proved difficult to elicit from study participants. All participants were asked to indicate the scope of such an assessment (see appendices 15-17) but had difficulty in stating precisely what information would be most helpful in exploring women's sexual adjustment or recovery after treatment completion, particularly within the time constraints of busy follow-up clinics.

Analysis of the interview transcripts from health professionals, women and their partners suggested that the core elements of sexual assessment in the clinic should include questions about:

▪ The woman's current relationship context, if any
▪ Any fear the woman may have about resuming sexual intercourse
▪ The types of sexual difficulties women may have experienced post-treatment
▪ The potential changes to sexual behaviour likely / necessary to accommodate the woman / couple's changed sexual life after cancer

Women agreed with health professionals' views that attempts to address women's sexual concerns during acute treatment were not always helpful (section 10.2) and recommendations were made for questions about sexual recovery to be raised approximately two to three months after treatment completion. However, because individual women were likely to follow different patterns, rates and degrees of post-treatment recovery it was considered important for questions about sexual recovery to be
repeated at key follow-up meetings across the initial 12 months of the women’s follow-up period. This would be more likely to identify women who were experiencing persistent disruption to their sexual well-being together with those finding such disruption distressing for them and/or their partner. Being able to identify women/couples with more persistent difficulties and those who were distressed would also allow health professionals to target those most likely to benefit from onward referral or intervention within the practice reality of scarce health care resources.

In addition to suggested improvements to the assessment of sexual morbidity in the clinic setting, health professionals also considered it important to develop clear referral systems and care protocols to ensure a more systematic and comprehensive approach to the management of women’s sexual difficulties after cancer treatment (section 10.4). This was deemed important from both a professional and ethical perspective whereby service should be capable of responding to the sexual problems elicited through improved routine assessment. Not only would this prevent the feeling of “impotence” that health professionals felt in assessing a need that they could not respond to, but it would also ensure that women’s sexual difficulties received due attention from practitioners and services capable of offering specialist sexual health interventions either within or beyond the cancer centre.

Importantly, women identified a need for greater inclusion of their partners in information giving and enquiries about patient’s sexual recovery after cancer treatment (section 10.1). This would require modification to practitioners’ current care philosophy which focuses on the woman as opposed to the couple as the context for clinical discussions about sexuality. This exclusion of spouses or intimate partners from the clinical assessment of patient’s social support needs has also been found in research conducted in palliative care settings, where one would imagine the focus of comprehensive care or service delivery to be the couple or family unit as opposed to the patient alone (Quinn et al. 2004).

It may be that before women’s partners can be usefully included in clinical discussions about sexual concerns, there is a need for staff development that enhances practitioner confidence and skills in working with couples. Such education is useful in addressing the sensitive issues of boundary management, confidentiality, couple communication
A popular proposal made by both health professionals and women in this study was to address the perceived service deficits within existing resources through the creation of a separate clinic led by an appropriately qualified clinical nurse specialist. This clinic would be run in parallel with the women's medical follow-up review and could follow one of a number of different models of service provision including a separate sexual health and menopause clinic or a clinic for the assessment and management of radiotherapy or cancer treatment late effects more broadly.

The majority of women stated a preference for their sexual information and support needs to be addressed by an appropriate member of their treatment team as opposed to being sent to a specialist sexual counselling service where knowledge of the contribution made by their oncological problem(s) may not be well known or understood (sections 10.3 & 10.4). This model of integrated sexual health service provision in oncology is not yet prevalent in the United Kingdom (White, 2007) but has been implemented in centres both in the Netherlands and the United States, although evidence of their efficacy is not yet available (Krychman, 2006; Incrocci, 2007b).

For reasons mentioned previously (section 10.3) a specialist nurse was identified as the most suitable oncology team member to offer this proposed service to women. Continuity of personnel, preferably a female practitioner and someone they knew and trusted who was kind as well as being a "specialist" was considered most important by women (Williams, 2001; Sardaki & Rosenqvist, 2001). It was interesting to note that specialist knowledge about female sexual difficulties and their management was not specifically mentioned by women as an important criterion for service improvement. It is unclear from the findings of this study as to whether or not this simply reflected women's lack of awareness of the type of specialist knowledge or training normally required to fulfil the role of a specialist in sexual medicine or psychosexual therapy. Alternatively this finding may represent a reluctance to view the psychosexual counsellor as an "expert" thus legitimising the gaze on women's sexual recovery and challenging a health care system marked by biomedical hegemony that renders female sexual concerns after cancer as unimportant, illegitimate and "not a medical problem" (Foucault, 1973; Hordern & Street, 2007a). From a Foucauldian perspective the failure by medicine, nursing and health care management in oncology to recognise the legitimacy of knowledge about women's sexual recovery renders sexual rehabilitation practice and practitioners
"invisible", "powerless" and thus vulnerable to persistent professional and economic marginalisation within the cancer centre (Foucault, 1973).

11.5 Summary of key findings

The findings of this study indicate that in the two cancer centres where this research took place, the clinical assessment of female sexual difficulties was not a core element of routine medical follow-up after radical pelvic radiotherapy for women with gynaecological (cervical or endometrial) or non-gynaecological (anal or rectal) malignancies.

Findings also suggest that individual practitioner and organisational development based upon a re-construction of the nature of women's changed sexual lives after cancer may be necessary before an inclusive and systematic approach to women's sexual health assessment and management in oncology could be achieved. Inevitably the introduction of any clinical assessment methodology for women's sexual health to current practice settings would be unlikely to succeed due to a lack of practitioner comfort in the discussion of women's sexual concerns, a lack of identifiable resources and the limited availability of specialist expertise within the cancer centre. As a consequence one of the original aims of this study, that of developing and piloting an integrated physical and psychosexual assessment methodology for use in routine clinical practice, could not be achieved.

The majority of health care professionals and women interviewed in this study believed that treatment related female sexual difficulties could be addressed more effectively in a separate clinic offered in parallel to routine medical follow-up. Opinions differed, however, regarding the specific model of such provision.

This ethnography has been successful in identifying some of the practitioner and organisational reasons for the neglect of female sexual well-being as a core element of post-treatment rehabilitation and cancer survivorship in women treated for pelvic malignancy. The concluding chapter of this thesis (chapter 12) offers recommendations for further research and practice development arising from the detailed analysis of this ethnographic data. It is believed that these recommendations may contribute to improvement in the current ad hoc and disparate approach to the clinical assessment and subsequent management of treatment induced female sexual difficulties in oncology follow-up.
Chapter 12: Conclusions and Recommendations

In keeping with the underlying philosophy of both feminist research and critical ethnography, this study has identified and discussed findings that not only increase our understanding of the nature and meaning of female sexual difficulties after cancer treatment, but how the clinical assessment and management of treatment-induced sexual difficulties might be improved in practice. In this final chapter I have identified the theoretical and methodological contribution of this study to knowledge that informs the assessment and management of female sexual difficulties in oncology. The limitations of this study are outlined in relation to both the choice of focused ethnography as a methodology and the challenge of study recruitment in exploring a sensitive research topic such as sexuality. The implications of these research findings for cancer policy, clinical practice, cancer service provision and the specialist education of health professionals are explored. This chapter concludes with recommendations for the development of future research that could address the paucity of evidence regarding the clinical assessment and management of women's sexual difficulties after cancer.

12.1 Theoretical and Methodological Contribution

This study has conducted a comprehensive exploration of what has been, to date, a relatively under-researched aspect of women's recovery following cancer treatment.

One of the strengths of this research is that it offers a synthesis of biomedical and sociological perspectives on the study of female sexuality after cancer. Hence this work offers a more thorough analysis and interpretation of the topic than is possible through adherence to any single theoretical perspective. A consequence of this synthesis of perspective is that study findings describe and interpret both the essentialist (functional) and socially constructed (subjective) elements of women's changed sexual lives after cancer treatment.

In adopting social constructionism as the underlying theoretical perspective for data analysis and interpretation I have identified limitations in the application of Foucault's ideas (1973, 1990a, 1990b, 1992) to the comprehensive study of human sexuality. Social constructionism fails to take account of the biological and anatomical realities of pelvic changes created by radiotherapy and their consequences for sexual function. This omission is not just important theoretically, but clinically where sexual assessment may
reveal an organic basis for many of the sexual difficulties experienced by the women in this study. I have proposed that the comprehensive study of female sexuality in oncology requires an integration of both essentialist and social constructionist perspectives (DeLamater & Shibley Hyde, 1998) in order to capture the complexity and abstract nature of the female sexual response in both health and illness. This proposed theoretical and research approach is in stark contrast to the biological determinism that shapes the study of erectile dysfunction and has already been shown to be deficient in its application to female sexual dysfunction (Tiefer, 2006).

The inclusion of male partners in this study created an opportunity for triangulation of perspective on altered sexuality as experienced by both the woman and her partner. Incorporating the partner’s voice also enables us to explore the interpersonal dimensions of women’s sexual lives, an aspect normally excluded from biomedical research on female sexual dysfunction in oncology. Hence this research has addressed each of the three key components of Hawton’s (1985) model of psychosexual practice in exploring the integration of physical, psychological and interpersonal dimensions of women’s sexuality after cancer.

In contrast to the majority of the medical and nursing literature on this topic the findings of this study also explored factors that adversely affect the delivery of sexual rehabilitation after cancer from both an organisational and practitioner perspective in seeking to understand the challenges faced by practitioners operating within inflexible, resource limited clinical contexts. This new knowledge may be important in creating a better understanding as to why there has been so little improvement in the delivery of sexual health care in oncology despite research publications on this topic dating back to the 1980s.

To date there have been four publications that have arisen directly from the research discussed in this thesis (see appendix 20). Congruent with the disciplinary synthesis of this research one paper has been published in a clinical oncology journal (White, 2008a) one has been published in a cancer nursing journal (White, 2008b) and one in a sexology journal (White, 2007). These papers have begun a process of research dissemination in exploring the need to improve the clinical assessment and management of female sexual morbidity after pelvic radiotherapy through work with different disciplinary groups whose evidence base is dominated by contrasting scientific paradigms. The fourth publication is a patient information booklet entitled: “Pelvic radiotherapy in women:
possible late effects” published by Cancer Research UK and Cancerbackup (Cancerbackup, 2007 ISBN: 1-905384-73-4). Patient information booklets about radiotherapy late effects for both men and women receiving pelvic radiotherapy were developed by a pelvic radiotherapy information steering group, of which I was a member. This group was chaired by Dr. Peter Blake, a consultant clinical oncologist who was a collaborator in this research and whose patients participated in the study. The booklet for women arose as a direct result of findings from this study whereby women had commented on the paucity of detailed information about sexual difficulties associated with pelvic radiotherapy. As a consequence this booklet, together with web-based patient information resources at Cancerhelp UK, now offers women a more detailed account of the sexual and other consequences of radical pelvic radiotherapy and their management.

Interim findings from this research have also been presented at national nursing research, cancer nursing, gynae-oncology and colorectal nursing meetings, European and international cancer nursing and oncology meetings and at national psychosexual therapy and international sexology meetings.

My methodological contribution has been to demonstrate originality in using my skills as a psychosexual therapist to enhance the depth of disclosure by study participants, while at the same time maintaining participant safety. This increased depth of disclosure about women’s experiences of sexual recovery has yielded particularly rich data for analysis, despite the sensitive nature of this research topic. Interpretation of interview data has subsequently led to a more comprehensive understanding of the diversity of women and couple’s pre and post-treatment sexual lives than would have been possible through data generated by dominant methods adopted in biomedical studies, such as surveys or controlled clinical trials (Tourangeau & Yan, 2007).

The inclusion of data from male participants as both the sexual partners of women and as health professionals within a study informed by feminist theory may also be seen as an important theoretical and methodological contribution. As Peters et al. (2007) argue, inclusion of the male voice in research on couples is imperative if we are to progress our knowledge and ideas about the experience of health and illness on the couple dyad. Furthermore, these authors recognise, as I have through my practice as a psychosexual therapist, that both men and women can experience the negative effects of oppressive power, regardless of their sexuality or sexual orientation.

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I have also demonstrated methodological originality in adopting a mixed method approach to data analysis in combining the use of SPSS (version 14) for participant observation data and NVivo (version 2.0) for analysis of in-depth interviews. Furthermore this focused ethnography generated a large and complex data set that was a challenge to analyse, interpret and present within the context of a time-limited ethnographic study.

12.2 Limitations of the study

As this was a focused ethnography it was not possible to explore the wider cultural system of the cancer centre within which the oncology follow-up clinic was situated. Hence this study offered a more boundaried and time-limited exploration of sexual recovery during one specific phase of the women's cancer journey. However, as can be seen from the quality and volume of data presented in this thesis, this study represents an in-depth focused ethnographic account of participants' experiences in facing the challenges inherent to the clinical assessment of women's changed sexual lives after cancer.

Due to the challenges associated with researching a sensitive topic within a relatively limited time frame, it was not possible to recruit a more diverse sample of participants. Hence the sample of women who took part in this study lacked the ethnic and religious diversity necessary to create a more culturally responsive narrative of the construction of female sexuality after cancer. Our understanding of the male partner's perspective and hence our appreciation of the impact of cancer treatment on the couple relationship is also restricted by the small homogeneous sample of male partners who took part in this research.

I was unable to recruit patient and partner participants from research site B within the time constraints of the study and so it was not possible to offer a comparison of service experiences across two contrasting cancer centres as originally intended. This sampling difficulty also reduced opportunities for data triangulation regarding data collected from site B through participant observation and health professional interviews. However, data generated from participant observation in clinics and from interviews with health care professionals at research site B suggest that the perspectives offered by women in research site A are likely to be broadly comparable.

One further limitation of this study relates to the narrow perspective offered by data generated through a single semi-structured interview with participants, as opposed to the more comprehensive developmental picture that can emerge from sampling data at
different points across the women's cancer treatment journey and from using a less structured interview approach. This may have offered a more complete picture of the processes of women's sexual recovery across time and could have further enhanced the level of rigour in this study. Despite these limitations, however, this focused ethnography generated a substantial data set for analysis and thus offers a more detailed exploration of the research topic than would be achieved through adoption of a positivist methodology.

12.3 Implications for healthcare policy and practice

When the original NHS cancer plan was published in 2000 there was an urgent need to address the under-investment in British cancer services that had led to the UK achieving lower survival rates for many of the major cancers compared to its European counterparts (DH, 2000). As a result of substantial improvements in both survival rates and services arising from implementation of the NHS Cancer Plan there was a need to review both cancer outcomes and the provision of services within the context of new NHS systems of commissioning and financial management. As a result of this review, the Cancer Reform Strategy (DH, 2007) outlined a five year programme of work to further improve the experience of people affected by cancer. Chapter five of the Cancer Reform Strategy (DH, 2007) recognises the increasing numbers of people that are "living with and beyond cancer." For the first time cancer survivorship has been recognised as a key policy priority area for the department of health to address. This increased emphasis on the quality of life and well-being of survivors in government policy is a result of recent research findings that indicate a higher incidence of chronic illness and disability among people who have survived cancer treatment, compared to those without a cancer diagnosis (Hewitt et al. 2003). Furthermore, research by Macmillan Cancer Support (2006) suggested that people who have been treated for cancer find the emotional consequences of this illness far more difficult to manage than the physical effects of their illness and treatment. Findings from this survey have indicated that cancer services and health care practitioners do not recognise the emotional distress patients and their families are experiencing and this can result in unmet needs. Patients who took part in this survey also indicated that their relationships and sexual lives were adversely affected by the experience of cancer treatment but that support in these domains of their recovery was again not available.
In 2008 NHS Improvement launched its National Cancer Survivorship Initiative (NCSI) and within this service improvement strategy there are a number of workstreams that are pertinent to the focus of this study, namely the need to improve the clinical assessment and management of the sexual consequences of cancer treatment. One of seven workstreams that will specifically address the domain of sexual morbidity is entitled: “Detecting, recording and managing the late effects of treatment”. This two year NHS work programme aims to develop a framework for the identification and management of late consequences of cancer treatment and the findings of this study could contribute to the evidence base for the clinical assessment and documentation of female sexual difficulties arising from pelvic cancer treatment. More specifically, the findings from this study offer a detailed account and interpretation of women and couple’s subjective lived experience of altered sexuality after cancer and as such contribute important insights to survivorship scholarship in oncology.

In considering the implications of these findings for oncology practice it is important that any change to clinical services that more effectively addresses the sexual consequences of pelvic cancer treatment for women must take account of the fact that fear of disease recurrence and the need to prioritise a woman’s survival will always take precedence over sexual recovery in oncology. Hence models of clinical service provision and staff attitudes must reflect the sensitivity of this aspect of rehabilitation within the personal context of the women’s illness, prognosis and specific relationship characteristics. It is appropriate that medical follow-up focuses on disease surveillance and biomedical aspects of acute and late treatment effects. However, what this may mean is that we should ensure the provision of psychosocial and psychosexual aspects of the woman’s illness experience takes place in an alternative service delivery context, by personnel who are able to offer that expertise and time within a busy clinical environment.

In relation to the conduct of sexual health assessment, these findings have demonstrated that the introduction of a paper or computer delivered assessment format alone would be insufficient to improve the assessment of sexual morbidity in practice. What needs to accompany the introduction of any assessment method are formalised referral and care pathways for the provision of different levels of patient information, clinical interventions and sexual counselling services supported by appropriate staff development as outlined in section 12.4.
If specialist nurses are deemed to be the most appropriate staff group to take forward the delivery of psychosexual assessment and intervention strategies within the cancer centre then they will need staff development and supervision that supports them to re-frame or re-construct female sexuality, thus releasing the assessment of women's sexuality from its current biomedical "straight jacket". More specifically this would include a shift in practice philosophy from one of individual care to the delivery of sexual recovery strategies that address the needs of the couple as well as the woman affected by the sexual consequences of treatment.

Health care systems and referral pathways also require scrutiny to ensure that professional staff groups operate in a complementary relationship with each other as opposed to any dominant group acting as sole gatekeepers for patient's access to specialist services.

Inherent to the development of new models of survivorship, treatment late effects or sexual morbidity services will be a need to address the current funding streams that currently exclude financial recognition of nurse-led services and rehabilitation care provision. It is hoped that the National Cancer Survivorship Initiative (2008) will address specific funding barriers to the development of more responsive cancer survivorship services.

12.4 Implications for Health Professional Education and Development

The findings of this study are consistent with others published in the field of sexuality in health care in identifying the persistent discomfort clinicians experienced in discussing sexual issues within their clinical role as doctors, nurses and therapy radiographers. Hence there are a number of implications for staff education and support if we are to improve the clinical assessment of female sexual difficulties in oncology practice.

These findings suggest that the majority of clinicians have difficulty in managing the boundaries and dynamics inherent to engaging a couple as opposed to individual patients / women in the clinical discussion of sexual morbidity. Thus health professionals may benefit from both theory and communication skills development related to working with couples as offered in psychosexual therapy training where working with couples is seen as the dominant therapeutic strategy (D'Ardenne & Morrod, 2003). Clinical colleagues may also benefit from communication skills training that enhance their ability to talk about a range of sensitive human health and illness topics, including sexual expression.
Health professionals working in oncology do not currently have a comprehensive theoretical or practical knowledge of the underlying mechanisms that create female sexual difficulties after multi-modal treatment, particularly those emanating from the psychological and interpersonal domains. There is also a lack of knowledge about the types of sexual morbidity prevalent among women with a non-gynaecological diagnosis. Hence there is a need to improve the theoretical knowledge of clinicians through provision of brief clinically focused education initiatives that include knowledge of the physical, psychological and interpersonal dimensions of female sexual morbidity. Furthermore, clinicians indicated that if they had knowledge of relevant clinical interventions they would be more likely to enquire about women’s sexual concerns. Hence education provision that addressed the biomedical, psycho-educational and psycho-sexual interventions currently used in the management of female sexual difficulties both within and outside the field of oncology may support practitioners to alter their current practice.

Inevitably it remains difficult to offer the philosophical and reflective approaches necessary for practitioners to develop an understanding of patients’ subjective experience of illness and treatment within time-limited, competency-based health care curricula. Furthermore, as argued by Waterhouse (1996), effective practice that addresses the more subjective aspects of patient’s health care needs, such as sexuality, results from a complex interplay of learning and practice in both classroom and clinical settings. The application of theoretical knowledge in practice may be enhanced by the provision of clinical supervision that supports health professional development and practice in what is currently a challenging and marginal element of clinical practice. This could be achieved by the establishment of local inter-disciplinary seminar groups such as those advocated by the Psychosexual Nurse’s Association, using a Balint style training approach. Nurses who participate in this type of seminar training reported increased confidence to address the psychosexual issues arising from their practice with patients (Wells, 2000).

From a practical perspective, health professionals in oncology may feel more confident to enquire about sexual difficulties experienced by their patients if they were also more informed about local and national referral services and specialist organisations that address female sexual difficulties beyond the field of oncology.

12.5 Implications for Further Research

As identified from the literature discussed in chapter two, there is a relative paucity of clinical research that addresses female sexual difficulties after cancer treatment,
particularly among women with a non-gynaecological cancer diagnosis. Furthermore, biomedical research to date has tended to exclude detailed exploration of the psychological and interpersonal dimensions of women's sexual recovery as a consequence of both methodological and theoretical restrictions.

As Basson (2000) and Tieffer (2006) have already articulated, female sexuality is fundamentally different from male sexuality and thus it should not be assumed that research methodologies used to study pharmacological interventions for male sexual dysfunction will automatically be the most appropriate approach for the study of more subjective aspects of female sexuality such as loss of sexual desire, dyspareunia, orgasmic changes or reduced sexual satisfaction.

Studies that use mixed methods and incorporate qualitative methodologies are more likely to generate greater depth of data that can better capture the subjective elements of female sexual expression. I would therefore recommend that future research explores the relational and psychological domains of sexual recovery in conjunction with the organic elements of sexual difficulty or "dysfunction".

Improved understanding of the nature of female sexual difficulties after cancer may then lead us to develop valid and reliable clinical assessment methods for female sexual difficulties associated with pelvic cancer treatment. In any evaluation of a clinical assessment methodology it is imperative that the knowledge and skills of the practitioners conducting such an assessment are explored in order to identify the factors that influence the feasibility of using such a methodology in practice from an individual perspective. The findings of this study also emphasise the importance of appreciating the barriers to discussing sexual issues that emanate from the organisations within which such clinical assessment takes place. I would suggest that greater understanding of the influence of organisational culture, health care systems and resource implications is needed to appreciate the reasons why formal clinical assessment strategies for treatment related sexual difficulties are so challenging to implement in routine practice.

Despite an emphasis on the development of clinical interventions from funding bodies and clinicians it is imperative that we improve assessment strategies first in order to create a more detailed understanding of the prevalence and nature of female sexual difficulties associated with cancer treatment.

In considering future research areas that should be financially supported clearly there is a need for intervention research that addresses the management of female sexual difficulties after pelvic cancer treatment. This research should address the systems of care...
delivery required to implement new clinical management strategies for female sexual difficulties in addition to individual practice development issues.

Arising from the recommendations made in section 12.4, there is also a need to conduct further research that identifies the most effective staff development approaches to improve communication about sensitive topics and the ability to work effectively with couples in a clinical context.

The findings of this study suggest that it is inappropriate to develop and pilot a clinical assessment methodology for use in the cancer centres that took part in this research because of the very low levels of routine sexual morbidity assessment achieved in practice. However, analysis of these findings has led to identification of the components of a model psychosexual assessment and management intervention that could be evaluated through future post-doctoral research. This assessment and management intervention comprises three integrated components as outlined in Table 12.1.

<table>
<thead>
<tr>
<th>Component</th>
<th>Content</th>
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<tbody>
<tr>
<td>4 Stage Clinical Assessment of Sexual Difficulties</td>
<td>Questions relevant to assessment of sexual morbidity within context of current relationship, treatment and illness context at key time points post-treatment (6 weeks, and 3, 6, 9, 12, 18 &amp; 24 months)</td>
</tr>
<tr>
<td>Structured Patient Information &amp; Clinical Service Provision</td>
<td>Provision of patient information (verbal, written &amp; web-based) related to sexual impact of treatment, clinical services and use of specialist referral pathways based on existing resources (where possible) and linked to individualised assessment outcomes</td>
</tr>
<tr>
<td>Staff Development &amp; Support</td>
<td>Individual or small group coaching based on a training needs analysis to ensure competent delivery of the structured assessment and clinical management strategy. Access to appropriate clinical supervision to provide support for personal and professional development associated with role change / expansion</td>
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</table>

From a methodological perspective it may be that an appropriate research design for a future study that seeks to implement and evaluate a novel psychosexual assessment and management intervention within a clinical setting would be action research, using the
data from this thesis as the basis (McCormack et al. 2004). Action research is a form of collaborative enquiry that has proved particularly useful not only in developing individual practitioners but making the necessary cultural changes to organisational systems that so often stultify practice innovation.

12.6 My Ethnographic Journey

The experience of undertaking this research has already contributed to my personal learning in a number of ways. Conducting a focused ethnography has enabled me to appreciate the important contribution that qualitative methodologies can make to the study of complex, socially constructed concepts or phenomena in health care, such as sexuality. As a cancer nurse I had been surrounded by the cultural product of logical positivism and to a large extent this influenced both my knowledge base and clinical practice in the assessment and management of “female sexual dysfunction” in oncology. Throughout this ethnography I have struggled with the cognitive dissonance created by keeping “a foot in each camp” as I tried to construct an authentic picture that embraced the multiple realities of women’s changed sexual lives after cancer treatment. These tensions have been played out in the processes of conducting ethnographic research, in academic supervision and in the creation of this ethnographic ‘product’. In reading this thesis I hope the reader will be able to appreciate multiple perspectives on women’s sexual lives after cancer treatment, and in so doing can begin to contemplate and perhaps even embrace alternative models of both clinical research and practice in beginning to explore this neglected field of work.

The experience of this research is already influencing my personal practice as both a cancer nurse and psychosexual therapist in the ways in which I have broadened my clinical gaze. This has created space for women and their partners to personally construct the meanings they ascribe to their experience of going through cancer treatment and the resultant consequences for their sexual expression and relationships. Through subsequent co-construction of the nature and meaning of individual and couple’s sexual difficulties the negotiation of therapy goals and mutually agreed therapeutic strategies are shaped.

Planned research dissemination activities at a local, national and international level create additional opportunities to raise professional awareness about the relative neglect of women’s sexual well-being after cancer treatment. Local research dissemination activities
have the additional benefit of being able to engage directly with research participants in discussing the feasibility of changes to current services so that women's sexual concerns can be more readily identified and responded to.

Finally, as a member of the late effects of treatment workstream of the NHS Improvement National Cancer Survivorship Initiative (NCSI, 2008) I hope to use the findings of this research to influence both the practice and culture of sexual morbidity assessment and management within this new cancer policy initiative.

In these ways it may be possible to challenge the dominant construction of female sexual morbidity in oncology and to begin a process of re-construction that can more readily accommodate and respond to the multiple realities of women's changed sexual lives as they "live with and beyond cancer."

The value of this ethnographic study lies in its ability to give voice to the unique experiences of women and couples as they explored the sexual and relationship consequences of pelvic cancer treatment. The findings from this study offer an in-depth qualitative insight into the meaning of these sexual changes for women and men's lives and challenge both oncology professionals and organisational structures to address the current neglect of this sensitive and complex aspect of cancer rehabilitation and survivorship.
Glossary of Terms

**Abdomino-perineal resection of the rectum:** Surgical resection of the lower rectum and associated lymphatics through both an abdominal and separate perineal incision. Removal of the whole rectum necessitates the creation of a permanent colostomy.

**Adhesions:** The joining or ‘sticking together’ of normally unconnected body structures or organs by bands of fibrous tissue. Adhesions often develop in a part of the body treated by surgery and / or radiotherapy.

**Adjuvant:** A treatment that is added to the primary treatment to enhance its effectiveness in eradicating or controlling an illness or disease process.

**Anterior resection of the rectum:** Surgical removal of the upper rectum and associated lymphatics and anastomosis of the remaining large bowel. A temporary colostomy is sometimes used to reduce the risk of anastomotic leakage while the tissues are healing and the stoma is reversed once healing is confirmed.

**Biomedicine:** Employing the principles of biology, biochemistry, physiology and other basic sciences to solve problems in clinical medicine.

**Brachytherapy:** The delivery of ionising radiation in close proximity to the tumour through placement of devices within body tissue or a body cavity. In this thesis this term is used to describe the temporary placement of radiation sources within the vagina to treat cervical or endometrial cancer.

**Chemo-radiotherapy:** The delivery of cytotoxic chemotherapy and radiotherapy over the same treatment time frame to increase the efficacy of tumour control through a synergistic impact on cancer cells.

**Essentialism:** Philosophical doctrine of essences; the doctrine that things have an essence or ideal nature that is independent of and prior to their existence.

**External beam radiotherapy:** The delivery of ionising radiation at a distance from the tumour usually using a linear accelerator to deliver the maximum planned dose to the patient’s tumour, while minimising the radiotherapy dose to the skin and other adjacent body structures.

**Feminine Care:** Provision of vaginal dilators and related instruction about their use following pelvic radiotherapy treatment.

**Fibrosis:** A thickening and scarring of connective tissue that follows tissue damage caused, in the case of pelvic cancer treatment, by surgery and radiotherapy.

**Heteronormative:** A term used to indicate that the underlying assumption applied to a concept is that heterosexual orientation is the dominant or ‘normal’ state or standard for society in defining human sexuality / sexual relationships.
**Hormone Replacement Therapy (HRT):** The provision of systemic or topical female hormones (oestrogen, progesterone +/- testosterone) to replace those lost through medically induced menopause in pre / peri-menopausal women treated for a pelvic malignancy.

**Moist Desquamation:** The third level of radiation induced skin damage whereby the basal layer of the epidermis has been unable to re-populate and the skin surface has peeled off leaving a raw area that is moist with serous exudate.

**Multi-modal Cancer Treatment:** The combination of different types of cancer treatment (surgery, radiotherapy, chemotherapy, targeted therapies, and biological therapies) to achieve the optimal effect upon disease control or eradication.

**Neo-adjuvant:** An additional treatment that is delivered prior to the principal treatment in order to enhance the effectiveness of that principal treatment.

**Social Constructionism:** A broad theoretical orientation in sociology that regards social facts, including especially social identities, as the products of socially and historically situated practices.

**Stenosis:** Narrowing of a hollow structure in the body. Used in the context of this study to describe the narrowing of the vagina that occurs as a result of radiation damage to the vaginal tissues.

**Telangectasia:** The presence of dilated capillaries on the surface of the skin or mucosa as a result of radiation damage to that body tissue. These dilated capillaries are fragile and can bleed with minimal trauma to the affected tissues.

**Treatment Late Effects:** Changes in body tissues and organs that develop over the weeks, months or years following completion of cancer treatment that give rise to symptoms or changes in function resulting in an adverse effect on the person experiencing these late effects.

**Vaginal Dilators:** Conical shaped devices with a flattened tip made of lightweight plastic in a range of sizes that are inserted into the woman's vagina to stretch the vaginal walls in order to break down the development of flimsy adhesions within the vaginal vault and reduce the likelihood of the development of vaginal stenosis following pelvic radiotherapy treatment.

**Vaginal Toxicity:** A collective term used in clinical oncology to refer to changes within the vagina induced by radiation damage. These changes can be acute or delayed in their onset and include fibrosis, stenosis, telangectasia and vaginitis.
References


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Appendix 1
Multi-Centre Research Ethics Committee (MREC) Approval Letter
Ms. Isabel D. White  
Cancer Research-UK Nursing Research Training Fellow  
University of Surrey  
European Institute of Health & Medical Sciences (EIHMS)  
5th Floor, Duke of Kent Building  
Stag Hill, Guildford, Surrey  
GU2 7TE  

Dear Ms. White  

Full title of study: Development of an Integrated Psychosexual Clinical Assessment Strategy for Women Receiving Pelvic Radiotherapy  
REc reference number: 05/MRE11/20  

Thank you for your letter of 09 June 2005, responding to the Committee’s request for further information on the above research and submitting revised documentation.  

The further information has been considered on behalf of the Committee by the Chair.  

Confirmation of ethical opinion  

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.  

The favourable opinion applies to the research sites listed on the attached form. Confirmation of approval for other sites listed in the application will be issued as soon as local assessors have confirmed they have no objection.  

Conditions of approval  

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.  

Approved documents  

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
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<td></td>
<td>08 April 2005</td>
</tr>
<tr>
<td>Investigator CV - Isabel White</td>
<td>1</td>
<td>01 March 2005</td>
</tr>
<tr>
<td>Protocol</td>
<td>1</td>
<td>01 March 2005</td>
</tr>
<tr>
<td>Letter from Sponsor Funding Letter</td>
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<td>13 July 2004</td>
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<td>Peer Review</td>
<td></td>
<td>22 April 2005</td>
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<tr>
<td>Compensation Arrangements Insurance Policy Cover</td>
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<td>01 January 2005</td>
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</table>
Management approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R&D Department for the relevant NHS care organisation.

Notification of other bodies

The Committee Administrator will notify the research sponsor that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/MRE11/20 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project,

Yours sincerely

Mrs Clair Wright
Acting Administrator

Email: metropolitanmrec@uhl.nhs.uk
Enclosures: Standard approval conditions, Site approval form (SF1)
The notes column may be used by the main REC to record the early closing of a site (where notified by the Chief Investigator or sponsor), the suspension or extension of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.

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<tr>
<th>Date of Favourable Opinion for this Site</th>
<th>Site Assessor</th>
<th>Site Area of Research</th>
<th>Research Site</th>
<th>Post</th>
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<tr>
<td>27/06/2005</td>
<td></td>
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The favourable opinion was given a favourable ethical opinion by Metropolitan MREC on 27 June 2005. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.

**Development of an Integrated Psychosocial Clinical Assessment Strategy for Women Receiving Pelvic Radiotherapy**

<table>
<thead>
<tr>
<th>Full Title of Study</th>
<th>Chief Investigator</th>
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<td></td>
<td>Mrs. Isabel D. White</td>
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<th>Issue Number</th>
<th>REC Reference number</th>
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<tbody>
<tr>
<td>27 June 2005</td>
<td>1</td>
<td>05MRE1/1:20</td>
</tr>
</tbody>
</table>

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from siteassadors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

**List of Sites with a Favourable Ethical Opinion**

Metropolitan MREC
Appendix 2
Research Site A Committee for Clinical Research (CCR)
(Research & Development) Approval Letter
Thank you for your application to the Committee for Clinical Research. The Committee acknowledged this is an MREC study and would like to thank Isabel White for presenting your application.

The Committee requested the following:
1) Confirmation that the Patient Information Sheet will have name on it.

The Committee approved the application, subject to satisfactory responses to the above.

Please note that the patients participation in this study should be recorded on the "Maintain CCR Protocols (CCRPAT)" computer system on the HIS and that the completed consent form bearing the relevant research Ethics Committee protocol number should be kept in case notes and in the trial master file.

There is no longer a need for you to send a copy of consent forms to the R&D Office.

The R&D Office will activate your project on HIS once all outstanding documentation has been received and you will then be notified.

Yours sincerely
Appendix 3
University of Surrey Research Ethics Approval Letter
26 July 2005

Ms Isabel White
PhD Student
E I H M S

Dear Ms White

Development of an Integrated Psychosexual Clinical Assessment Strategy for Women Receiving Pelvic Radiotherapy (EC/2005/73/EIHMS) – FAST TRACK

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 26 July 2005

The list of documents reviewed and approved by the Committee under its Fast Track procedure is as follows:-

Document Type: Application
Dated: 11/07/05
Received: 15/07/05

Document Type: Approval Letter form the Metropolitan Multi-centre REC
Version: 1
Dated: 27/06/05
Received: 15/07/05

Document Type: Application Form for the NHS Research Ethics Committee
Dated: 08/04/05
Received: 15/07/05

Document Type: Research Protocol
Version: 2
Dated: 06/05
Received: 15/07/05

Document Type: Appendix 1 – Letter to Participants
Version: 1
Received: 15/07/05

Document Type: Appendix 2 – Invitation to Participate
Version: 2
Received: 15/07/05
This opinion is given on the understanding that you will comply with the University’s Ethical Guidelines for Teaching and Research, and with the conditions set out below.

1. That the Patient Information Sheet indicates that this research is being undertaken as a doctoral study.

2. That you confirm what contingencies are in place, should you interview participants in a non secure location (such as private home), i.e. minimally there should be some form of logging arrival and departure from known address.
The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected, with reasons.

I would be grateful if you would confirm, in writing, your acceptance of the conditions above, enclosing amended sections of the protocol.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

\[Signature\]

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethics Committee
    Dr S Faithfull, Supervisor, EIHMS
    Dr H Allan, Supervisor, EIHMS
Appendix 4
Research Site B Research & Development Approval Letter
Dear Ms White

TRUST APPROVAL OF A RESEARCH PROJECT

I have pleasure in enclosing the completed Trust Research Project Approval Form. This means that your project may be hosted by the Trust. Before you commence your project you must have received approval from the Local Research Ethics Committee.

Evidence Based Practice

Research Governance is designed to promote a positive culture of quality, respect and learning: to have value over and above detecting misconduct and fraud. In order that your project contributes to the knowledge base within the NHS you are:

- Strongly encouraged to disseminate your findings through publication and presentations
- Take appropriate measures to protect any intellectual property that may arise
- Collaborate with the R&D Office on providing information on the progress of the project

Important Documents

Please ensure that you keep together in a safe place the following:

- Your Research Ethics Approval letter
- The enclosed Trust Registration Form with signatures indicating approval
- A Register of all patients/samples/measurements made
- An accurate dated Laboratory Notebook for all laboratory projects
- A Patient Information Sheet
- A Patient Consent Form (completed forms must be filed on the Patient Record Files)
- An Honorary Contract - if you are not a member of the Trust staff

Required Standards

The research supported by the Trust must fall within a framework of Research Governance to ensure the research is of a high quality and that the risks, in particular to the participants, are effectively identified and managed. A number of support mechanisms are available to assist researchers meet the standards of quality and safety including information for contacts for Health & Safety, Data Protection and Risk Assessment are given in the introductory leaflet for staff on research (yellow). You must observe the following during the conduct of your project:

- Inform the Ethics Committee and the Trust R&D Office of any changes in the protocol
- Conform with the Data Protection Act and Trust Policies on Data Protection and Confidentiality
- Conform with the Health & Safety at Work Acts and Trust Policies on Health & Safety
- Report any adverse events associated with the project following the Trust Adverse Events Reporting system
- Place completed consent forms on the patient notes

I wish you every success with your research.
Appendix 5
Participant Observation Brief Patient Information Sheet
Research Study

Exploring the Content of Doctor – Patient Consultations in Radiotherapy Follow-up Clinics

IS THE PURPOSE OF THE STUDY?

The information sheet is to make you aware that there is a research study taking part in your outpatient clinic that aims to explore the content of doctor-patient discussions that take place during radiotherapy follow-up clinics. The researcher is called Isabel White and she is a qualified cancer nurse with a special interest in radiotherapy practice and the support of women after pelvic therapy treatment.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

You would like permission from you to sit and observe your consultation with the researcher. She will not take part in the consultation as she is there in a research observation capacity only. She is noting what topics doctors, patients, and partners (if they are present) raise during such consultations. There is a need for any physical or intimate examinations as part of your consultation and she will not be present during this examination and your privacy will be maintained.

DO I HAVE TO TAKE PART?

At the beginning of your consultation your doctor will ask you if you are willing to let the researcher sit in during your consultation. You are free to agree or refuse this request without there being any impact on the care and information you would normally receive.

DO I HAVE TO DO?

If the researcher is hoping to observe naturally occurring discussions it is important you do not change what you were going to raise with your doctor, just continue to discuss the issues you considered relevant/important to you.

MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

The Research & Development Committee, Local Research Ethics Committee, Consultants involved in your medical management and other relevant committees are aware of the study. However, your involvement in the study will not be communicated to any other personnel. Only the researcher will have access to observation notes and these will be stored securely in a locked office at the University of Surrey.

Information regarding your medical and personal details will be treated as strictly confidential and will only be used as relevant to the purpose of this study. Your name or identifying details are removed and will not be used on any reports produced from the study.
Exploring the Content of Doctor – Patient Consultations in Radiotherapy Follow up Clinics (continued)

IS ORGANISING AND FUNDING THE RESEARCH?

The study is funded by a nursing research training fellowship grant from the charity Cancer Research-UK. The chief investigator for the study, Isabel White, is funded by a nursing research award. The study is organised by a research team from the University of Surrey.

HAS REVIEWED THE STUDY?

The study has been approved by the Metropolitan Multi-centre Research Ethics Committee.

FACT FOR FURTHER INFORMATION

If you have any questions arising from taking part in this study you can contact the researcher as follows:

E: Isabel White
ESS: European Institute of Health & Medical Sciences (EIHMS)
University of Surrey, 5th Floor Duke of Kent Building
Stag Hill, Guildford, GU2 7TE, Surrey

I: i.white@surrey.ac.uk

Phone: 01483 - 684580

Thank you for considering taking part in this study.

Patient Information Sheet for Participant Observation Version 1 June 2005
Appendix 6
Participant Observation Framework
Appendix 6

Participant Observation Framework

Place: Environment – Artefacts, How does setting influence patient / professional experience?

Privacy for sensitive discussions to take place & for physical examinations (eg vaginal examination)

Time Availability Duration and frequency of clinic, number of patients booked in and number of clinicians present in clinic

Resources Presence / absence of relevant nurse specialists in primary diagnosis / RT treatment / sexual adaptation to cancer in clinic
Presence / absence of relevant written information (eg side effects of pelvic radiotherapy, use of vaginal dilators, sexual consequences of pelvic radiotherapy)
Presence / absence of information regarding sources of appropriate support / counselling regarding sexual concerns (eg CNS’s / Psychologists in local Trust, BACUP, RELATE, BASRT)

Actors: What happened? Behaviour, Demeanour, Interactions, Motivation
At what point in the woman’s treatment journey is this follow up appointment taking place? (3, 6, 12 or 24 months post RT)
Who conducts the follow up consultation?
Who establishes the agenda for discussion?
Is the woman’s partner present during consultation?
Is the woman’s partner involved in the consultation if present?

Activities: What took place? How was it managed? What topics / behaviours dominated?
What was Permissible versus Non-Permissible?
Who raises the discussion / assessment of radiotherapy side effects?
How is RT toxicity assessed? Recognised toxicity assessment method? Written checklist locally produced? Ad Hoc verbal assessment?
What components of RT toxicity / side effects are assessed?
Are late effects of pelvic RT addressed in assessment as relevant?
Are menopause / HRT issues assessed by HCP as relevant?
Who raises the discussion of sexual consequences of pelvic RT?
Are sexual consequences of pelvic RT elicited by HCP?
When in duration of consultation are more sensitive aspects of assessment conducted?
Is a physical examination conducted where appropriate? (eg vaginal examination)
What types of sexual concerns are enquired about / assessed in the follow up clinic and in what context are they discussed?
If sexual consequences are NOT discussed, would it have been relevant to have done so given the clinical / personal information known at time of consultation?
What aspects of the consultation are recorded in the patient’s medical notes?
Appendix 7

Participant Observation Schedule
Appendix 7

Clinic Consultation Participant Observation Content Schedule

Date / Research Site: ________________________________
Consultant: ______________________________________
Type of Clinic (New / On-Treatment / Follow-Up): ________________________________
Booked Patient Nos: ________________________________ Actual Attendees: ________________________________
Medical Staff Present: ________________________________ Nursing Staff Present: ________________________________

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P = Patient Initiated Topic PA = Partner Initiated Topic D = Doctor Initiated Topic

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Appendix 8
Patient Participant Study Invitation Letter
March 2005

Dear Participant Name,

I would like to ask you if you would consider taking part in a research study that is currently taking place at [Name of NHS Trust and Department].

The study is called: Assessing Sexual Issues in Women Receiving Pelvic Radiotherapy

As you will see from the attached study information leaflet, we are interested in how the symptoms or side effects of pelvic radiotherapy are assessed by health professionals involved in the follow up care of women who have received treatment for cervical, endometrial, bladder, rectal or anal cancers. Whilst the possible sexual consequences of cancer treatments is a private and sensitive topic it is also important for health care professionals to ensure that adequate information and support about this aspect of patient's lives is provided both during and following pelvic cancer treatment.

As you / your partner completed radiotherapy treatment between 3 months and 2 years ago we think you may be suitable to take part in this study.

This study has been approved to take place at [Name of NHS Trust] by the [Name of ethics committee and research & development committee]. Your / your partner's treatment team is also pleased to support this research as we believe it will help us to continue to develop staff and services so we can continue to offer a high quality of care and management for patients and their partners both during and following completion of radiotherapy treatment.

I would be grateful if you would be prepared to take the time to read the enclosed study information sheet and to consider whether or not you would feel able to assist us with this important research.

If you have any questions about the study or want to discuss any aspect of the information sheet further do contact the researcher, Isabel White, by post, phone or email as indicated. Once you have had the chance to consider your decision, or to discuss it with others where necessary, please complete the reply slip at the end of this letter or contact the researcher by email or phone to inform us of your decision.

Thank you for considering this request to take part in this study.

Yours Sincerely,

[Name of Patient Consultant]
[Designation of Consultant]
Appendix 8 (continued)

Reply Slip
Please do not hesitate to contact the researcher if you would like to discuss any aspect of this study prior to reaching an initial decision to take part.

Isabel White can be contacted as follows:

By Post: European Institute of Health & Medical Sciences (EIHMS)
University of Surrey
5th Floor, Duke of Kent Building
Stag Hill
Guildford GU2 7TE

By Phone: 01483-684580 (Direct Line / Answer phone messages accepted)

By Email: i.white@surrey.ac.uk

Name:.....................................................................................................................

Contact Address / Phone Number / Email:
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

I do / do not (please delete as appropriate) agree to take part in the research study called: Assessing Sexual Issues in Women Receiving Pelvic Radiotherapy.

If you agree to take part in this study the researcher will normally contact you to arrange an interview time / date that coincides with your next routine follow up appointment at the hospital where you received your radiotherapy treatment. If this is not convenient please do not hesitate to let the researcher know and she will make arrangements for the interview to take place at your convenience.
Appendix 9
Patient Study Information Sheet
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

WHAT IS THE PURPOSE OF THE STUDY?

We are interested in how the symptoms or side effects of pelvic radiotherapy are assessed by health professionals involved in the follow up care of women who have received treatment for cervical, endometrial, bladder, rectal or anal cancers. More specifically we would like to understand how the potential sexual impact of pelvic radiotherapy treatment is discussed by women and by those clinical staff providing their radiotherapy care. Whilst this is a private and sensitive topic it is also important for health care professionals to ensure that adequate information and support about this aspect of patient’s lives is provided both during and following pelvic cancer treatment.

Research that has been carried out to date in relation to pelvic radiotherapy symptom / side effect assessment has tended to focus on bladder and bowel side effects but has tended to omit the potential sexual and relationship consequences of women’s experience of pelvic cancer and its treatment.

This study explores the factors influencing clinical assessment of sexual concerns in cancer care and the key factors that women, their partners and health professionals believe should be incorporated into such an assessment.

Information provided by those participating in the study would then be used to design an assessment approach that can be used by women and health care professionals as part of routine radiotherapy follow up and rehabilitation. This assessment approach would then be tried out (a pilot study) with a small group of women and health professionals in a radiotherapy clinic to see if the assessment approach is practical for use in clinical settings and to ensure it generates information so that women can receive the most appropriate supportive care or rehabilitation post-treatment.

It is anticipated the study will take 2-3 years to complete.

WHY HAVE I BEEN CHOSEN?

You have been approached because you completed treatment for a pelvic cancer (cervical, endometrial, bladder, rectal or anal cancer) between 3 months and 2 years ago and are currently attending your hospital for routine medical follow up. You have been identified as suitable to take part in this study from your consultant’s clinic list and a brief review of your medical notes.

We hope to interview 40 women (20 maximum from 2 different NHS Cancer Treatment Centres) who have received pelvic radiotherapy alone or in combination with surgery or chemotherapy for the treatment of their cancer.
Appendix 9 (cont.)

We would also like to interview a smaller sample (10 maximum) of the partners of women who have completed treatment and agree to take part in the study because we believe they may have some additional information regarding how we could improve assessment of the information and support needs of couples coping with the experience of pelvic cancer and its treatment.

Finally we plan to observe radiotherapy follow up clinics and to interview health care professionals involved in radiotherapy treatment and care (10 maximum) to find out how they currently assess women attending their radiotherapy department and clinics and what changes, if any, they would make to patient assessment approaches.

DO I HAVE TO TAKE PART?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw from the study at any time without giving a reason.

A decision to withdraw at any time, or a decision not to take part, will not affect the type or standard of care you receive.

WHAT WILL HAPPEN TO ME IF I TAKE PART?
If you agree to take part in this study we would arrange to conduct a one hour interview in a private room close to the outpatient clinic on the day of your clinic appointment in order to minimise any inconvenience to you. If this arrangement is unsuitable for any reason we would be pleased to discuss an alternative convenient time and place for the interview to take place. You would normally be asked to take part in a single interview only.

If you agree the interview will be tape-recorded; otherwise detailed notes will be made during the interview.

The interview will ask you to talk about when, how and by whom the side effects of your radiotherapy treatment were discussed. More specifically the interview will ask you to talk about how the intimate or sexual relationship with your partner has been affected by your illness and its treatment, together with any suggestions you may have about how we could ensure your information and support needs are satisfactorily assessed by those health care professionals responsible for your care and follow up.

This is an exploratory study that will use interviews and observation of follow up clinics to find out how best to provide sensitive and appropriate assessment of the possible sexual and relationship consequences of pelvic radiotherapy.

The overall study will take 2-3 years to complete.

WHAT DO I HAVE TO DO?
You do not have to change any aspect of your lifestyle, health, medication, post-treatment care or follow up if you decide to take part in this study. What we ask of you is that you are willing to answer the questions asked in the interview in as full and honest a manner as you can.

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?
We do not anticipate that there are any risks associated with taking part in this study. If it does raise any issues that you would like to discuss further, we will be happy to provide information or suggest other specialist sources of advice.
Appendix 9 (cont.)

However, if you feel there are other circumstances that may have affected your experience (such as other illnesses) please feel free to discuss this with Isabel White, chief investigator, prior to taking part.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?
Taking part in this study is unlikely to benefit you directly. However, we hope that the information gained from you will help to improve the clinical assessment and subsequent provision of support and information for women and partners coping with the symptoms / side effects of pelvic radiotherapy treatment.

WHAT IF SOMETHING GOES WRONG?
We believe that this study is basically safe and do not expect you to suffer any harm or injury because of your participation in it.
If you are dissatisfied about any aspect of your involvement in this study you have the right to complain through the [Name of Hospital] Trust complaints procedure, a copy of which can be consulted on request.

Participation in this study will in no way affect your legal rights.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?
Your Consultant and General Practitioner are aware of the study and its focus.
Only the researchers will have access to the interview notes or tape recordings and these will be stored securely in a locked office at the University of Surrey. All information regarding your medical records will be treated as strictly confidential and for the purpose of this study will only be used to record relevant personal details (such as age and menopausal status) your diagnosis and the technical details of your radiotherapy treatment. You will be asked to give permission for us to record these details for research purposes. Your name or identifying details are removed and will not be used on any reports that are produced from the study.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?
The results of this study will be published in a report to the charity, Cancer Research-UK who is sponsoring this research. It is also anticipated that reports will be made to the relevant directorate / unit(s) of the two NHS Trusts where this study is taking place.
However, you will not be identified in any report or publication resulting from this study. The findings from this study are likely to be available early in 2007, a summary of which can be obtained from the chief investigator at the University of Surrey, who are organising this study. The study findings also contribute to the award of a PhD from the University of Surrey for the chief investigator (Isabel White) and will be presented in a thesis that will be retained by the University library.

WHO IS ORGANISING AND FUNDING THE RESEARCH?
This study is funded by a nursing research training fellowship grant from the charity Cancer Research-UK. The chief investigator for the study, Isabel White, is funded by this award. The study is organised by a research team from the University of Surrey in collaboration with the [Names of Research Sites].
Appendix 9 (cont.)
WHO HAS REVIEWED THE STUDY?
This study has been approved by the Metropolitan Multi-centre Research Ethics Committee, the [Research Site A] Research Ethics Committee, the [Research Site B] Ethics Committee and the University of Surrey Ethics Committee. In addition the study has been reviewed and approved by the [Research Site A] Committee for Clinical Research (CCR) and the [Research Site B] Research & Development Committee.

CONTACT FOR FURTHER INFORMATION
You will always be able to contact a researcher to answer any questions you may have, to discuss any concerns and/or to get advice:

Name: Isabel White
Address: European Institute of Health & Medical Sciences (EIHMS)  
University of Surrey, 5th Floor Duke of Kent Building  
Stag Hill, Guildford, GU2 7TE, Surrey
Email: i.white@surrey.ac.uk
Telephone Number: 01483 - 684580

Thank you for considering taking part in this study. You will be given a copy of this information sheet and of your signed consent form to keep.

June 2005 Patient Version 2
Appendix 10
GP Study Information Letter
March 2005

Dear Dr. 

Re: 

The above patient has agreed to participate in a study entitled:

**Development of an Integrated Psychosexual Clinical Assessment Strategy for Women Receiving Pelvic Radiotherapy**

We are interested in how the side effects of pelvic radiotherapy are assessed by health professionals involved in the follow up care of women who have received treatment for cervical, endometrial, bladder, rectal or anal cancers. More specifically we would like to understand how the potential sexual impact of pelvic radiotherapy treatment is discussed by women and by those clinical staff providing their radiotherapy care. Whilst this is a private and sensitive topic it is also important for health care professionals to ensure that adequate information and support about this aspect of patient's lives is provided both during and following pelvic cancer treatment.

This study explores the factors influencing clinical assessment of sexual concerns in cancer care and the key factors that women, their partners and health professionals believe should be incorporated into such an assessment.

Information provided by those participating in the study will be used to design an assessment approach that can be used by women and health care professionals as part of routine radiotherapy follow up and rehabilitation. This assessment approach would then be piloted with a small group of women and health professionals in a radiotherapy clinic to see if the assessment approach is practical for use in clinical settings and to ensure it generates relevant information so that women can receive the most appropriate supportive care or rehabilitation post-treatment, an element of the NICE (2004) Supportive & Palliative Care Guidance for adults with cancer and the National Cancer Plan (DH, 2000).

Agreement to access patients at the [Name of Research Site A] and [Name of Research Site B] has been given by the consultants responsible for these women's management at their respective Trusts.

The study will include in-depth tape-recorded interviews with a maximum of 40 women and a sample of 10 of their partners. The interviewer (Isabel White) has experience of delivering psychosexual therapy and holds a qualification in this speciality in addition to being an experienced cancer nurse. She will conduct the interviews with sensitivity and ensure support for difficult discussions to take place.

Participants who have unresolved issues that require further discussion will be referred back to relevant members of their clinical team (either consultant medical staff, clinical nurse specialist or general practitioner) to establish the most appropriate intervention / support required.
Appendix 10 (cont.)

This study is conducted by Isabel White, Cancer Research-UK Nursing Research Training Fellow, European Institute of Health & Medical Sciences (EIHMS), University of Surrey, Guildford in collaboration with [Name of collaborating consultant at Research Site A] and [Name of collaborating consultant at Research Site B].

This study has been approved by the Metropolitan Multi-centre Research Ethics Committee, the [Research Site A LREC], the [Research Site B LREC] and the University of Surrey Ethics Committee. In addition the study has been reviewed and approved by the [Research Site A R&D Committee] and the [Research Site B R&D Committee].

If you have any questions regarding this patient's participation or would like any further information about the study please contact the chief investigator:

Isabel White
Address: European Institute of Health & Medical Sciences (EIHMS)
University of Surrey, 5th Floor Duke of Kent Building
Stag Hill, Guildford, GU2 7TE, Surrey

Telephone Number: 01483 - 684580
Email: i.white@surrey.ac.uk

Yours Sincerely,

Isabel White
Cancer Research-UK Nursing Research Training Fellow
Appendix 11
Participant Consent Form
CONSENT FORM

Title of Project: Assessing Sexual Issues in Women Receiving Pelvic Radiotherapy

Name of Researcher: Isabel White

1. I confirm that I have read and understand the information sheet dated June 2005 (version 2) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care or legal rights being affected.

3. I understand that sections of my medical notes may be looked at by responsible individuals from the University of Surrey or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

4. I agree to take part in the above study.

5. I agree to my interview for this study being tape recorded

6. I would like my interview tape returned to me on completion of the study

OR

7. I would like my interview tape destroyed by the researcher on completion of the study

Patient Participants Only

8. I agree to my partner being approached to take part in the above study and confirm that they are aware of my participation.

9. I know that the researchers will tell my general practitioner (GP) about my part in the study.

Name of Participant __________________________ Date __________ Signature __________________________

Researcher __________________________ Date __________ Signature __________________________

Name of Person taking consent (if different from researcher) 1 for participant; 1 for researcher; 1 to be kept with hospital notes __________________________ Date __________ Signature __________________________
Appendix 12
Partner Participant Information Sheet
Invitation to Participate in a Research Study (Partner)

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

WHAT IS THE PURPOSE OF THE STUDY?
We are interested in how the symptoms or side effects of pelvic radiotherapy are assessed by health professionals involved in the follow up care of women who have received treatment for cervical, endometrial, bladder, rectal or anal cancers. More specifically we would like to understand how the potential sexual impact of pelvic radiotherapy treatment is discussed by women and by those clinical staff providing their radiotherapy care. Whilst this is a very private and sensitive topic it is also important for health care professionals to ensure that adequate information and support about this aspect of patient and partner's lives is provided both during and following pelvic cancer treatment.

Research that has been carried out to date in relation to pelvic radiotherapy side effect assessment has tended to focus on bladder and bowel symptoms but has tended to omit the potential sexual and relationship consequences of women's experience of pelvic cancer and its treatment. In particular the specific impact on partners is rarely included in such studies.

This study explores the factors influencing clinical assessment of sexual concerns in radiotherapy care and the key factors that women, their partners and health professionals believe should be incorporated into such an assessment.

Information provided by those participating in the study will be used to design an assessment approach that can be used by women and health care professionals as part of routine radiotherapy follow up and rehabilitation. This assessment approach would then be tried out (a pilot study) with a small group of women and health professionals in a radiotherapy clinic to see if the assessment approach is practical for use in clinical settings and to ensure it generates information so that women can receive the most appropriate supportive care or rehabilitation post-treatment.

It is anticipated the study will take 2-3 years to complete.

WHY HAVE I BEEN CHOSEN?
You have been approached because you are the partner of a woman who completed treatment for a pelvic cancer (cervical, endometrial, bladder, rectal or anal cancer) between 3 months and 2 years ago. She has already taken part in this study and has agreed that we may approach you to take part.

We hope to interview 40 women (20 maximum from 2 different NHS Cancer Treatment Centres) who have received pelvic radiotherapy alone or in combination with surgery or chemotherapy for the treatment of their cancer.
Appendix 12 (cont.)
We would like to interview a sample (10 maximum) of the partners of women who have agreed to take part in the study because we believe you may have some additional information regarding how we could improve assessment of the information and support needs of couples coping with the experience of pelvic cancer and its treatment.

Finally we plan to observe radiotherapy follow up clinics and to interview health care professionals involved in radiotherapy treatment and care (10 maximum) to find out how they currently assess women attending their radiotherapy department and clinics and what changes, if any, they would make to patient assessment approaches.

DO I HAVE TO TAKE PART?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw from the study at any time without giving a reason.
A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your partner receives.

WHAT WILL HAPPEN TO ME IF I TAKE PART?
If you agree to take part in this study we would arrange to conduct a one hour interview in a private room close to the radiotherapy outpatient clinic on a convenient date and time in order to minimise any inconvenience to you. If this arrangement is unsuitable for any reason we would be pleased to discuss an alternative convenient arrangement for the interview to take place.
You would normally be asked to take part in a single interview only.
If you agree the interview will be tape-recorded; otherwise detailed notes will be made during the interview.
The interview will ask you to talk about when, how and by whom the symptoms / side effects of treatment were discussed with you as the partner of a woman receiving pelvic radiotherapy treatment. More specifically the interview will ask you to talk about how the intimate or sexual relationship with your partner has been affected by her illness and its treatment, together with any suggestions you may have about how we could ensure your information and support needs are satisfactorily assessed by those health care professionals responsible for her care and follow up.

This is an exploratory study that will use interviews and observation of follow up clinics to find out how best to provide sensitive and appropriate assessment of the possible sexual and relationship consequences of pelvic radiotherapy.
The overall study will take 2-3 years to complete.

WHAT DO I HAVE TO DO?
You do not have to change any aspect of your lifestyle or health if you decide to take part in this study. What we ask of you is that you are willing to answer the questions asked in the interview in as full and honest a manner as you can.

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?
We do not anticipate that there are any risks associated with taking part in this study. If it does raise any issues that you would like to discuss further, we will be happy to provide information or suggest other specialist sources of advice.
However, if you feel there are other circumstances that may have affected your experience (such as other illnesses) please feel free to discuss this with Isabel White prior to taking part.
WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?
Taking part in this study is unlikely to benefit you directly. However, we hope that the information gained from you will help to improve the clinical assessment and subsequent provision of support and information for women and partners coping with the symptoms / side effects of pelvic radiotherapy treatment.

WHAT IF SOMETHING GOES WRONG?
We believe that this study is basically safe and do not expect you to suffer any harm or injury because of your participation in it.
If you are dissatisfied about any aspect of your involvement in this study you have the right to complain through the [Name of Hospital] Trust complaints procedure, a copy of which can be consulted on request.

Participation in this study will in no way affect your legal rights.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?
Your partner’s Consultant and General Practitioner are aware of the study and its focus.
Only the researchers will have access to the interview notes or tape recordings and these will be stored securely in a locked office at the University of Surrey. All information about you obtained through this study (such as age, relevant medical history and relationship status) will be treated as strictly confidential and will not be divulged to any third party. You will be asked to give permission for us to record these details for research purposes. Your name or identifying details are removed and will not be used on any reports that are produced from the study.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?
The results of this study will be published in a report to the charity, Cancer Research-UK who is sponsoring this research. It is also anticipated that reports will be made to the relevant directorate / unit(s) of the two NHS Trusts where this study is taking place.
However, you will not be identified in any report or publication resulting from this study. The findings from this study are likely to be available early in 2007, a summary of which can be obtained from the chief investigator at the University of Surrey, who are organising this study.

The study findings also contribute to the award of a PhD from the University of Surrey for the chief investigator (Isabel White) and will be presented in a thesis that will be retained by the University library.

WHO IS ORGANISING AND FUNDING THE RESEARCH?
This study is funded by a nursing research training fellowship grant from the charity Cancer Research-UK. The chief investigator for the study, Isabel White, is funded by this award. The study is organised by a research team from the University of Surrey in collaboration with the [Research Site A] and the [Research Site B].

WHO HAS REVIEWED THE STUDY?
This study has been approved by the Metropolitan Multi-centre Research Ethics Committee, the [Research Site A] Research Ethics Committee, the [Research Site B] Ethics Committee and the University of Surrey Ethics Committee. In addition the study has
Appendix 12 (cont.)
been reviewed and approved by the [Research Site A] Committee for Clinical Research (CCR) and the [Research Site B] Research & Development Committee.

CONTACT FOR FURTHER INFORMATION
You will always be able to contact a researcher to answer any questions you may have, to discuss any concerns and/or to get advice:

Name: Isabel White
Address: European Institute of Health & Medical Sciences (EIHMS)
University of Surrey, 5th Floor Duke of Kent Building
Stag Hill, Guildford, GU2 7TE, Surrey
Email: i.white@surrey.ac.uk
Telephone Number: 01483 - 684580

Thank you for considering taking part in this study. You will be given a copy of this information sheet and of your signed consent form to keep.

June 2005 Partner Version 2
Appendix 13
Health Professional Participant Information Sheet
Invitation to Participate in a Research Study (Health Care Professional)

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

WHAT IS THE PURPOSE OF THE STUDY?
We are interested in how the side effects of pelvic radiotherapy are assessed by health professionals involved in the follow up care of women who have received treatment for cervical, endometrial, bladder, rectal or anal cancers. More specifically we would like to understand how the potential sexual impact of pelvic radiotherapy treatment is discussed by women and by those clinical staff providing their radiotherapy care. Whilst this is a private and sensitive topic it is also important for health care professionals to ensure that adequate information and support about this aspect of patient’s lives is provided both during and following pelvic cancer treatment.

Research that has been carried out to date in relation to pelvic radiotherapy side effect assessment has tended to focus on bladder and bowel side effects but has tended to omit the potential sexual and relationship consequences of women’s experience of pelvic cancer and its treatment.

This study explores the factors influencing clinical assessment of sexual concerns in clinical oncology and the key factors that women, their partners and health professionals believe should be incorporated into such an assessment.

Information provided by those participating in the study will be used to design an assessment approach that can be used by women and health care professionals as part of routine radiotherapy follow up and rehabilitation. This assessment approach would then be piloted with a small group of women and health professionals in a radiotherapy clinic to see if the assessment approach is practical for use in clinical settings and to ensure it generates relevant information so that women can receive appropriate supportive care or rehabilitation post-treatment.

It is anticipated the study will take 2-3 years to complete.

WHY HAVE I BEEN CHOSEN?
You have been approached because you provide management / care to women who have completed pelvic radiotherapy for cervical, endometrial, bladder, rectal or anal cancer between 3 months and 2 years ago and are currently attending your hospital for routine medical follow up. You have been identified as suitable to take part in this study because of your direct involvement in the clinical assessment of radiation side effects and the follow up care of this group of women.

We would like to both observe radiotherapy follow up clinics and to interview health care professionals involved in radiotherapy treatment and care (10 maximum) to find out how you
Appendix 13 (cont.)
currently assess women attending the radiotherapy department and clinics and what
types, if any, you would make to patient assessment approaches.
We hope to interview 40 women (20 maximum from 2 different NHS Cancer Treatment
Centres) who have received pelvic radiotherapy alone or in combination with surgery or
chemotherapy for the treatment of their cancer.
We also intend interviewing a smaller sample (10 maximum) of the partners of women
who have completed treatment and agree to take part in the study because we believe
they may have some additional information regarding how we could improve assessment of
the information and support needs of couples coping with the experience of pelvic cancer
and its treatment.

DO I HAVE TO TAKE PART?
It is up to you to decide whether or not to take part. If you do decide to take part you will be
given this information sheet to keep and be asked to sign a consent form. If you decide to
take part you are still free to withdraw from the study at any time without giving a reason.

WHAT WILL HAPPEN TO ME IF I TAKE PART?
This is a qualitative study that adopts participant observation of follow up clinics and
interviews to find out how radiation side effects are currently assessed and to consider how
to ensure appropriate assessment of the possible sexual and relationship consequences of
pelvic radiotherapy.

If you agree to take part in this study it is possible that you would be asked to allow the
researcher to observe a routine radiotherapy follow up clinic where field notes would be
made of the conduct, content and context of the consultations with women post-pelvic
radiotherapy. You would not be expected to alter the routine type of management and
care normally provided during such a consultation, nor is there a need for any preparation for
this observation.
You may also be asked to agree to take part in a one hour interview in a private room
close to the radiotherapy outpatient clinic on a day and time that you are at work, while
causing you minimal inconvenience. If this arrangement is unsuitable for any reason we
would be pleased to discuss an alternative convenient time and place for the interview to
take place.
You would normally be asked to take part in a single interview only. If you agree, the
interview will be tape-recorded; otherwise detailed notes will be made during the interview.
The interview will ask you to talk about when, how and by whom the side effects of
patient’s radiotherapy treatment is discussed. More specifically the interview will ask
you to talk about how you currently assess the impact of illness or treatment on the
intimate or sexual relationship of the woman and her partner. The interview will then ask you
for any suggestions you may have about how the clinical assessment of pelvic
radiotherapy side effects could be developed.
The overall study will take 2-3 years to complete.

WHAT DO I HAVE TO DO?
You do not have to change any aspect of your patient management or service delivery
if you decide to take part in this study. What we ask of you is that you are willing to answer
the questions asked in the interview in as full and honest a manner as you can.
Appendix 13 (cont.)

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?
We do not anticipate that there are any risks associated with taking part in this study. If it does raise any issues that you would like to discuss further, we will be happy to provide information or suggest other specialist sources of advice. However, if you feel there are other circumstances that may have affected your experience please feel free to discuss this with Isabel White, the chief investigator, prior to taking part.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?
Taking part in this study is unlikely to benefit you directly. However, we hope that the information gained from you will help to develop the clinical assessment and subsequent provision of support and information for women and partners coping with the side effects of pelvic radiotherapy treatment.

WHAT IF SOMETHING GOES WRONG?
We believe that this study is basically safe and do not expect you to suffer any harm or injury because of your participation in it. If you are dissatisfied about any aspect of your involvement in this study you also have the right to complain through the Trust complaints procedure, a copy of which can be consulted on request.

Participation in this study will in no way affect your legal rights.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?
Your Trust Research & Development Committee, Local Research Ethics Committee, Consultants involved in the management of this group of women and other relevant senior personnel are aware of the study and its focus. However your involvement in the study will not be communicated to any other personnel. Only the researchers will have access to the interview and observation notes or tape recordings and these will be stored securely in a locked office at the University of Surrey.

All information regarding your professional details will be treated as strictly confidential and will only be used as relevant to the purpose of this study. You will be asked to give permission for us to record these details for research purposes. Your name or identifying details are removed and will not be used on any reports that are produced from the study.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?
The results of this study will be published in a report to the charity, Cancer Research-UK who is sponsoring this research. It is also anticipated that reports will be made to the relevant directorate / unit(s) of the two NHS Trusts where this study is taking place. However, you will not be identified in any report or publication resulting from this study. The findings from this study are likely to be available early in 2007, a summary of which can be obtained from the chief investigator at the University of Surrey, who are organising this study.
The study findings also contribute to the award of a PhD from the University of Surrey for the chief investigator (Isabel White) and will be presented in a thesis that will be retained by the University library.
WHO IS ORGANISING AND FUNDING THE RESEARCH?
This study is funded by a nursing research training fellowship grant from the charity Cancer Research-UK. The chief investigator for the study, Isabel White, is funded by this award. The study is organised by a research team from the University of Surrey in collaboration with the {Names of Collaborating Research Sites}.

WHO HAS REVIEWED THE STUDY?
This study has been approved by the Metropolitan Multi-centre Research Ethics Committee, the [Research Site A] Research Ethics Committee, the [Research Site B] Ethics Committee and the University of Surrey Ethics Committee. In addition the study has been reviewed by the [Research Site A] Committee for Clinical Research (CCR) and the [Research Site B] Research & Development Committee.

CONTACT FOR FURTHER INFORMATION
You will always be able to contact a researcher to answer any questions you may have, to discuss any concerns and/or to get advice:

Name: Isabel White
Address: European Institute of Health & Medical Sciences (EIHMS)
          University of Surrey, 5th Floor Duke of Kent Building
          Stag Hill, Guildford, GU2 7TE, Surrey
          Email: i.white@surrey.ac.uk

Telephone Number: 01483 - 684580

Thank you for considering taking part in this study. You will be given a copy of this information sheet and of your signed consent form to keep.
June 2005 Health Care Professional Version 2
Appendix 14
Demographic Details Data Sheet for Patient Participant Study Refusals
Appendix 14

Demographic Details Summary: Patient Interview Refusals

Refusal Code: ___________ Letter Date: ____________________

Age: < 30 years □ 30-40 yrs □ 41-50 yrs □ 51-60 yrs □ 61-70 yrs □ 71-80 yrs □ > 80 yrs □

Ethnicity: ________________________ Religion: ______________________

Relationship Status: Married □ Current Partner □ Widow □ No Partner □ Not Known □

Primary Diagnosis: ____________________________

Clinical Stage: ____________________________

Summary of Cancer Therapy (with completion dates):

Time since completion of Pelvic RT (months): 3 months □ 6 months □ 12 months □ 24 months □

Co-morbid Medical History Relevant to Study Focus:

- Diabetes Yes □ No □
- Menopause Yes □ No □
- Depression Yes □ No □
- Anxiety Yes □ No □
- Other Yes □ No □

Please specify: ____________________________

Sexual Concerns / Difficulties Recorded in Medical Records: Yes □ No □

Please specify: ____________________________
Appendix 15
Interview Outline for Patient Participants
Appendix 15

Interview Schedule (Patient)

1. Could you begin by telling me what is most memorable to you about the time surrounding your radiotherapy treatment?

2. What do you remember being told about the symptoms of pelvic radiotherapy to expect during or immediately following your period of treatment?

3. How accurate was that explanation in relation to your specific experience of any of these symptoms?

4. What do you remember being told about the delayed symptoms of pelvic radiotherapy that may occur weeks / months following completion of your treatment?

5. How accurate was that explanation in relation to your specific experience of any of these symptoms?

6. What influence, if any, has your experience of cancer and its treatment had on your relationship with your partner?

7. What would your partner say about the influence of your illness and treatment on your relationship together?

8. How would you describe the sexual aspects of your relationship prior to your diagnosis and cancer treatment?

9. Has your illness and radiotherapy treatment had any influence on the sexual aspects of your relationship(s)?

NB Depending on response to this question there would then be individualised questions relating to exploration of illness / treatment effects on:

sense of femininity / sense of sexual identity
sexual desire / interest
sexual arousal / vaginal lubrication
orgasmic experience
sexual satisfaction

10. What would your partner say about the influence of your illness and radiotherapy treatment on the sexual aspects of your relationship?

11. Can you tell me what you remember being asked about during your radiotherapy follow up clinic appointments by any of the health care professionals caring for you?
Appendix 15

12. During your follow up clinic appointments, did anybody ask specifically about the impact of any of the radiotherapy symptoms / side effects on the sexual aspects of your relationship?

13. Did you ask about the impact of your illness or treatment on the sexual aspects of your relationship? If so, how were those questions responded to?

14. What information and support about the potential impact of cancer or its treatment on the sexual aspects of your relationship did you receive prior to starting radiotherapy treatment?

15. What information and support about the potential impact of cancer or its treatment on the sexual aspects of your relationship did you receive during or following completion of your radiotherapy treatment?

16. What information did you and your partner find most helpful, and why?

17. What were the most useful sources of support and information regarding sexual concerns for you and your partner?

18. Was there anything missed that you would have liked to have discussed?
Appendix 16
Interview Outline for Partner Participants
Interview Schedule (Partner)

1. Could you begin by telling me what is most memorable to you about the time surrounding your partner's radiotherapy treatment?

2. What do you remember being told about the symptoms of pelvic radiotherapy to expect during or immediately following your partner's period of treatment?

3. How accurate was that explanation in relation to your partner's experience of any of these symptoms?

4. What do you remember being told about the delayed symptoms of pelvic radiotherapy that may occur weeks / months following completion of your partner's treatment?

5. How accurate was that explanation in relation to your partner's experience of any of these symptoms?

6. What influence, if any, has the experience of your partner's illness and its treatment had on your relationship together?

7. What would she say about the influence of her illness and treatment on your relationship together?

8. How would you describe the sexual aspects of your relationship with your partner prior to her diagnosis and radiotherapy treatment?

9. Has her illness and radiotherapy treatment had any influence on the sexual aspects of your relationship?

NB Depending on response to this question there would then be individualised questions relating to exploration of illness / treatment effects on the woman's partner in relation to his / her:

- sexual desire / interest
- sexual arousal / erection
- orgasm / ejaculation
- experience / frequency of intercourse
- sexual satisfaction

10. Did you ever accompany your partner to any of her radiotherapy follow up appointments? If Yes, can you tell me what you remember being asked about during the clinic by any of the health care professionals caring for her?

11. During her follow up clinic appointments, did anybody ask specifically about the impact of any of the radiotherapy symptoms / side effects on the sexual aspects of your relationship together?
12. Did you ask about the impact of her illness or treatment on the sexual aspects of your relationship? If so, how were those questions responded to?

13. What information and support about the potential impact of cancer or its treatment on the sexual aspects of your relationship did you receive prior to starting radiotherapy treatment?

14. What information and support about the potential impact of cancer or its treatment on the sexual aspects of your relationship did you receive during or following completion of her radiotherapy treatment?

15. What information did you and your partner find most helpful, and why?

16. What were the most useful sources of support and information regarding sexual concerns for you and your partner?

17. Was there anything missed that you would have liked to have discussed?

18. What changes (if any) would you like to see in the discussion of radiotherapy symptoms / side effects or in the provision of information and support for women experiencing pelvic radiotherapy and their partners?
Appendix 17
Interview Outline for Health Professional Participants
Appendix 17


Interview Schedule (Health Care Professional)

1. What do you consider the priority elements to include in your assessment of the potential acute and late side effects of pelvic radiotherapy treatment for the routine follow up of these women?

2. What, if any, physical assessments routinely take place as part of these follow up consultations?

3. At which point(s) in the cancer patient journey do such assessments normally take place?

4. Where do such assessments normally take place?

5. Who is normally involved in the conduct of these assessments?

6. Are partners normally involved in such discussions? (Ask to elaborate on response re rationale for inclusion / exclusion)

7. Are there any challenges / barriers associated with conducting clinical assessment of the psychosexual effects of pelvic radiotherapy in this group of women?

8. What information, if any, is given to women and their partners about the nature of sexual changes / difficulties associated with the acute and late effects of pelvic radiotherapy treatment? [NB This question would be asked where this has not been offered as part of question1]

9. What information, if any, is given to women and their partners regarding sources of support / counselling should they require further information / support regarding sexual concerns / difficulties associated with their illness / treatment?

10. How do you view the adequacy of current assessment approaches in eliciting the needs of women and their partners in respect of illness / treatment related sexual concerns / difficulties?

11. Are there aspects of the current service provision for this patient group that require further development / resources and if so, in what respect?

12. Are there elements of clinical assessment / practice you would like to include in radiotherapy follow up that are currently missing?

13. How did your training / professional development contribute to your current practice in respect of your competence and confidence in conducting such an assessment?
Appendix 18
Example of NVivo model of data category and sub-category set
Altered sexual satisfaction

Loss of desire

Orgasmic change

Fear of resuming sexual intercourse

Alienated sexual identity

Living with a changed sexual life

Sexual Pain
Appendix 19
Interview Linked Data Sets / Cases
Appendix 19: Interview Linked Data Sets / Data Cases

Patient Participants (n = 24)

<table>
<thead>
<tr>
<th>Case No.</th>
<th>PT</th>
<th>PTNR</th>
<th>HCP</th>
<th>Notes</th>
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</thead>
<tbody>
<tr>
<td>1 NHS</td>
<td>PT01</td>
<td>N/A</td>
<td>HCP02</td>
<td>CVX (No partner)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>HCP11</td>
<td>Chernobyl &amp; nuclear war imagery</td>
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<tr>
<td>2 NHS</td>
<td>PT02</td>
<td></td>
<td>HCP03</td>
<td>ANUS (Partner)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>HCP07</td>
<td>Distancing in relationship</td>
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<tr>
<td>3 NHS</td>
<td>PT03</td>
<td>N/A</td>
<td>HCP02</td>
<td>ENDO (No partner)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>HCP11</td>
<td>Invisible Vagina. Needs of single women post-RT</td>
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<tr>
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<td>PT04</td>
<td>N/A</td>
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<td></td>
<td></td>
<td></td>
<td>HCP11</td>
<td>Fear of resuming sex / bleeding</td>
</tr>
<tr>
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<td>PT05</td>
<td></td>
<td>HCP02</td>
<td>ENDO (Partner)</td>
</tr>
<tr>
<td></td>
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<td>HCP11</td>
<td>Good Sexual Adjustment</td>
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<td>HCP02</td>
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<td>Good Sexual Adjustment</td>
</tr>
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<td>HCP03</td>
<td>RECTUM (Partner)</td>
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<td>Fear of bleeding /stenosis present</td>
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<tr>
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<td>HCP03</td>
<td>ANUS (No partner)</td>
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<td>HCP07</td>
<td>Masturbation as sexual expression</td>
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<td>PTNR01</td>
<td>HCP08</td>
<td>RECTUM (Partner)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Good sexual adjustment / positive view of vaginal stenosis</td>
</tr>
<tr>
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<td>PT10</td>
<td>PTNR02</td>
<td>HCP01</td>
<td>RECTUM (Partner)</td>
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<td>HCP07</td>
<td>Being sexual for partner's sake</td>
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<td>PT11</td>
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<td>HCP02</td>
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<td>Sex not a priority in recovery after cancer</td>
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<td>HCP11</td>
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<td>Being sexual for partner's sake</td>
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<td>PTNR</td>
<td>HCP</td>
<td>Notes</td>
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<td>13</td>
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<td>Relationship difficulties, dyspareunia, loss of desire &amp; menopause symptoms</td>
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<td>HCP11</td>
<td>ENDO (Partner)</td>
</tr>
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<td>HCP02</td>
<td>ENDOPartner</td>
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<td>Lack of RT impact due to low sexual priority in pre-illness life</td>
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<td>Sexual pain, bowel side effects</td>
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<td>Sexual Myths, Dyspareunia &amp; support strategies</td>
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<td>Impact of vaginal stenosis</td>
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<td>HCP03</td>
<td>RECTUM (Partner)</td>
<td>Gender of HCP as barrier</td>
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