Women's experience of laparoscopic surgery in endometrial cancer: a phenomenological study

by

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Thesis

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PART ONE

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STATEMENT OF ORIGINALITY

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 Any ideas, data, images or text resulting from the work of others (whether published or unpublished) are fully identified as such within the work and attributed to their originator in the references, bibliography or in footnotes. This thesis has not been submitted in whole or in part for any other academic degree or professional qualification.
ABSTRACT

Aim: This study aimed to develop a description of the experience of laparoscopic surgery for endometrial cancer from the patient perspective.

Background: Laparoscopic surgery is increasingly used to treat early endometrial cancer where there are surgeons trained to perform the procedure. It is generally associated with low levels of morbidity and considered safe for cancer surgery but research is limited on quality of life and patient experience.

Method: Heideggerian hermeneutic phenomenology was used to explore the experiences of 14 women who had undergone the procedure in two South of England cancer centers. Unstructured taped interviews were transcribed and analysed using Colazzi's (1978) framework, which included returning to the participants for a validation interview.

Findings: A phenomenological description emerged from the five identified themes: having cancer, information and support, independence, normality and transfer of responsibility to the surgeon. The experience of laparoscopic surgery was shown to be overshadowed by the presence of endometrial cancer. Fear of cancer and lack of knowledge played a significant role in the need to trust the surgeon with the responsibility for decision making. Information needs were unique to the individual but focused on what would be done, what to expect and the practicalities of being in an unfamiliar situation and environment rather than treatment choices. Loss of control, vulnerability and dependence are associated with illness and surgery but early postoperative mobility and minimal pain facilitated a rapid return to independence and normality with the potential to significantly enhance wellbeing.
Conclusion: The findings of this study represent a phenomenological description of the essence of the experience of laparoscopic surgery for endometrial cancer. Understanding the significance of the cancer diagnosis and the role of the surgeon in decision making will enable healthcare professionals to deliver care that is responsive to the patient experience and encourage the use of treatments that maintain independence and normality.

Key Words: Nursing, Laparoscopic hysterectomy, Phenomenology, Interview, cancer care, Women's Health, endometrial cancer.
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Glossary and Definition of Terms

Adjuvant (treatment or therapy) – Treatment that is given in addition to the primary treatment.

Age-standardised – Age-standardised rates account for the absolute numbers of old or young people in a population. This ensures that differences in rates between geographical areas or over time do not simply reflect different age populations.

Atypical endometrial hyperplasia – An abnormal change in the cells of the endometrium which is associated with endometrial cancer in about 10% – 20% of cases.

Being – A Heideggerian term for the nature or meaning of a phenomenon.

Being-in-the-world – A Heideggerian phrase referring to the way human beings exist, act, or are part of the world.

Bracketing – (also known as phenomenological reduction and epcohé) A way of suspending one's beliefs and preconceptions in the reality of the world in order to study the essential structures.

Carcinoma – A malignant tumour that arises in the epithelial tissue that lines the internal and external surfaces of the body.

Cancer Network – A government funded organisation which has responsibility for the standard of NHS cancer services within a defined geographical area. There are currently 28 Cancer Networks in England.

Dasein – A Heideggerian term which refers to the aspect of humanness capable of wondering about its own existence or being.
**Deductive Research** - Involves starting from general principles and defining down to specific predictions.

**Distantiality** - A Heideggerian term for the aspect of humanness that makes us disturbed by deviation from the norm.

**Endometrium** - The name given to the tissue lining the womb, or uterus.

**Epistemology** - The theory of knowledge. The branch of philosophy concerned with the nature of knowledge.

**Epithelium** - The tissue that lines the cavities and surfaces of structures in the body and the outer surface.

**Epoché** - (also known as bracketing and phenomenological reduction) A way of suspending one’s beliefs and preconceptions in the reality of the world in order to study the essential structures.

**Essence (Wesen)** - In philosophy, essence is the attribute that makes an object what it fundamentally is, without which it loses its identity.

**Grade (of cancer cells)** - The degree of cellular differentiation, that is, how much cancer cells resemble or differ from normal cells under the microscope.

**Hermeneutics** - The theory and practice of interpretation.

**Histopathology** - A branch of pathology that deals with the tissue diagnosis of disease. It primarily involves the microscopic examination of tissue which has been removed in a biopsy or as part of a surgical procedure or at a post-mortem.

**Hysterectomy** - The surgical removal of all or part of the uterus.
Ileus – A temporary disruption to the normal peristalsis of the intestines, most commonly seen after abdominal surgery.

Incidence – The frequency with which a disease appears in a particular population or area.

Inductive Research – Involves starting from specific observations to define general rules.

Intentionality – The concept of intentionality was described by the philosopher Franz Brentano and can be defined as the "aboutness" or "directedness" which indicates the inseparable interconnectedness of the human being in the world. Whenever one thinks, one always thinks about something (Stevenson 2002).

Laparoscopy – A procedure in which a fiber optic instrument is introduced into the abdomen to perform a surgical procedure or to examine the abdomen and/or pelvis.

Laparotomy – A surgical procedure involving an incision through the abdominal wall to gain access to the abdominal and pelvic cavities.

Menopause – The point at which menstruation ceases because the ovaries no longer produce sex hormones. Defined as the time when there has been no menstrual period for a year and no other biological or physiological cause can be found. The menopause is often referred to as the period of time in which the process of cessation occurs. A menopause can occur naturally or be induced with the surgical removal of the ovaries or damage to the ovaries from radiation or drugs.

Metaphysics – A branch of philosophy concerning the principles of reality including the relationship between mind and matter.
**Metastasis** – Cancer which has spread from the primary site – metastatic disease.

**Morbidity** – The prevalence of a disease within a population. In cancer and clinical healthcare it also refers to the adverse effects caused by treatments.

**Mortality** – The quality of being mortal or destined to die. Mortality also refers to the death rate or the number of deaths in a defined group of people over a defined time.

**Myometrium** – The middle layer of the wall of the uterus that is made up of smooth muscle cells.

**Neoplasm** – Any abnormal new growth of cells, specifically where the growth is uncontrolled. Often called tumours, which may be benign or malignant.

**Oncology** – The study of cancer.

**Ontology** – The study or theory of the nature of being.

**Prevalence (in epidemiology)** – The total number of cases of a disease in a given population at a given time.

**Phenomenology** – The science of phenomena as experienced by the senses. Since the twentieth century, phenomenology has almost exclusively been used to describe the philosophical method and movement that had its origins in the work of the philosopher and mathematician Edmund Husserl.

**Phenomenological Reduction** – (also known as bracketing and epoché) A way of suspending one’s beliefs and preconceptions in the reality of the world in order to study the essential structures of the world.

**Stage (of disease)** – The extent to which a cancer has spread in the body.
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CHAPTER 1: INTRODUCTION

1.1 Introduction

Laparoscopic hysterectomy was first performed in 1988 (Reich et al. 1989) and recent studies have confirmed the relative safety and efficacy of this treatment for women with endometrial cancer (Walker et al. 2009). Although gynaecologists were quick to adopt this technology, the number of surgeons trained to perform the procedure remains low (Domingo & Pellicer 2009).

Despite evidence to suggest a positive perception of laparoscopic hysterectomy (Hart et al. 2001) and the increase in its use by some surgeons (Domingo & Pellicer 2009), there are no reported studies assessing this technology from the perspective of the women who have undergone the procedure. This gap in the literature, which is discussed in more detail in Chapter 3, forms the basis of this study.

This introductory chapter will present my reasons for undertaking research in this area of practice. The aims of the study, together with a summary of the components and findings are also presented here.

1.2 The Researcher

As a Clinical Nurse Specialist in gynaecological cancer I became interested in the use of laparoscopic surgery when one of four gynaecological cancer surgeons began performing the procedure and offering it to women in his care with

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1 Both of the laparoscopic surgeons involved in this study were male and gender specific language will be used in reference to these surgeons.
endometrial cancer. Despite being informed that the technique was relatively new and not widely practiced, these women were willing and even appeared keen to have their hysterectomy performed laparoscopically.

As a former Lead Nurse in cancer clinical trials, I considered how unusual it was for patients to be so enthusiastic about having what amounted to an experimental procedure, when current practice was well established, effective and relatively safe. My initial thoughts concerned what influenced women in their decision making and apparent preference for the treatment but it became clear that very little was understood about the experience itself.

There have been few changes in the surgical technique of hysterectomy since the first abdominal procedure was performed in the year 1843 (Sutton 1997). Being part of a team involved in the delivery of a new surgical technique offered a unique opportunity to study this modality in its infancy and develop an understanding of what it was like for women to be offered this treatment and undergo the procedure.

Secondary to this, I also considered the framework in which cancer services were delivered and how this impacted on access to specialist gynaecological cancer surgeons for women with endometrial cancer and the inequality that is inherent in a procedure that can only be performed by a small number of surgeons.

These reflections were developed in the initial part of the doctoral programme and were refined throughout in an iterative process with the help of supervision. These ideas represent the background to this research project.
1.3 Study Aims

Given that laparoscopic surgery in endometrial cancer is a relatively new procedure which is poorly understood from the perspective of women who are offered and undergo this treatment, this study aimed:

- To develop a description of the experience of laparoscopic surgery for endometrial cancer from the patient perspective.

Developing an understanding from the perspective of another requires attention to their experience and not the generation of a hypothesis by a researcher. Research methods based on an inductive approach were considered to be the most appropriate and phenomenology, which is concerned with understanding the world as we sense or interpret it, was the methodology chosen to achieve the study aim, the reasons for this are described in Chapter 4.

Research from the patient experience adds a new dimension to the literature regarding laparoscopic surgery. A patient focused understanding of the procedure can be used to define the priorities for women and provide a description of the surgery to inform and prepare women who are diagnosed with the disease and considering treatment options or about to undergo surgery. These findings can also be used to generate research questions developed from patient defined concerns and not those of researchers or clinicians. Finally, healthcare providers can use the patient experience to develop services based upon the needs of users as interpreted from their actual experiences.

1.4 Disease and Treatment

Chapter 2 introduces the subject of endometrial cancer and the treatments used to manage the disease. Epidemiological data places the disease in the context of
worldwide incidence, mortality and disease burden. The diagnosis and current
treatment recommendations are discussed, together with advances in surgery that
have led to the development of laparoscopic hysterectomy. The political drivers for
cancer services and patient choice in England are introduced as concepts relevant
to the issues facing women with endometrial cancer.

Cancer of the uterus, primarily the endometrium, is a relatively common cancer
with the highest incidence in Western industrialised nations (Parkin et al. 2005). As
lifestyles change and life expectancy increases globally, so does the incidence of
endometrial cancer because of its association with increasing age and obesity
(Boyle & Levin 2008). The disease tends to be diagnosed as early stage and
treatment, in the form of hysterectomy, is highly effective (Benedet et al. 2000).
Developments in laparoscopic surgery have led to the introduction of laparoscopic
hysterectomy as a treatment for endometrial cancer (Childers et al. 1993). However,
not all gynaecologists perform laparoscopic surgery and the skill or preference of the
surgeon is the major determinant of hysterectomy route (Domingo & Pellicer 2009).

1.5 Reviewing the Literature

The role of a pre-study literature review is debated in phenomenological
research and the reasons for this are presented in Chapter 3. In this study, an initial
literature review was carried out to ensure that the issues facing women having
laparoscopic surgery for endometrial cancer were understood, that no similar
studies had already been reported, to provide shape and focus to the study and to
be able to demonstrate this for ethical review. In keeping with phenomenological
methodology, as discussed in Chapter 4, the literature was then reviewed
throughout the course of the study as themes emerged and the findings were
integrated into the synthesis presented in Chapter 8.
The pre-study literature review identified four key areas in relation to laparoscopic hysterectomy for benign and malignant disease, these were, safety and efficacy, complications, cost effectiveness and some data on quality of life with regard to postoperative pain, mobility and functionality, together with length of hospital stay. A summary of these key areas is presented in Chapter 3. The pre-study literature review confirmed the lack of research on the patient experience in laparoscopic surgery in both endometrial cancer and benign disease.

1.6 Study Design

Chapter 4 introduces the concept of phenomenology as a philosophy and a research methodology. This chapter explains why the study aim of developing an understanding of laparoscopic surgery for endometrial cancer, was considered to be best suited to qualitative methods of data collection and analysis. This chapter continues with a description of the two main types of phenomenological research and why an Interpretive Heideggerian approach was taken.

Chapters 5 and 6 present a detailed description of the methods used to collect and analyse the data. Between February 2008 and July 2009, 14 women who had undergone laparoscopic surgery for endometrial cancer in two different cancer centres in the South of England, were interviewed. These face-to-face unstructured interviews were taped and the verbatim transcripts organised using Microsoft Excel. Colaizzi's (1978) framework was the data analysis tool used in this study and supervision with an experienced researcher in the qualitative approach, the keeping of a research diary, using the voice of the participants in the report and returning to the participants for validation of the interpretation, were methods employed to enhance rigour and trustworthiness as markers of research credibility.
1.7 Study Findings

Analysis of the data revealed five themes which represented the essence of the experience of laparoscopic surgery in endometrial cancer. The findings suggested that having cancer overshadowed and shaped all aspects of the surgical experience. Information and support needs were highly personal, based upon prior knowledge and experience but information was sought from healthcare professionals that helped the individual cope with the unfamiliarity of the situation, explaining what would happen, what to expect and how to cope in individual circumstances. The themes continued with independence and normality where the findings associated laparoscopic surgery with low levels of dependency and disruption to normal life. Finally, the participants described a process by which they came to trust the figure of the surgeon and engaged in the transfer of responsibility to the surgeon, whereby the participants could be relieved of uncertainty and the responsibility for decision making by the expert.

These findings are described in Chapter 7 using the words of the participants to demonstrate the interpretation. The findings form a narrative that represents what Colaizzi (1978) described as the exhaustive description of the experience and a statement of the fundamental structure or phenomenological description of laparoscopic surgery in endometrial cancer is presented as an integration and synthesis of the exhaustive description.

In Chapter 8, a synthesis of the findings in relation to the literature regarding the identified themes are discussed together with the implications for practice. Chapter 9 concludes with a summary of the study and considers the contribution that it makes to clinical practice and the literature on laparoscopic surgery for endometrial cancer,
as well as suggesting other areas of practice to which the study findings may be applicable.

1.8 Summary of Chapter

This chapter presented an overview of the background and development of this study. It has presented a summary of the components, conduct and findings. My own experience and interest has shaped this project from the initial idea to the completed portfolio. It represents my interpretation of the experience of laparoscopic surgery for endometrial cancer as described by 14 women who had undergone the procedure. Although this is my interpretation, the participants confirmed the findings and this, together with a structured analytical framework, supervision and audit trail, add to the credibility of the study.
CHAPTER 2: BACKGROUND

2.1 Introduction

Endometrial cancer is a serious condition but it can be effectively treated and cured in the majority of cases (Parkin et al. 2005). Women with endometrial cancer generally present with early disease and surgery, in the form of hysterectomy, is the recommended primary treatment (Bakkum-Gamez et al. 2008; Benedet et al. 2000; Department of Health (DH) 1999; Winter & Gosewehr 2006 online). Hysterectomy has traditionally been performed vaginally or through an abdominal incision but in 1988 the first hysterectomy using a laparoscope was performed (Reich et al. 1989). As this technique has developed and gynaecological surgeons have become more experienced at the procedure, women with endometrial cancer have been increasingly offered laparoscopic hysterectomy in the management of their disease (Schindlbeck et al. 2008; Seracchioli et al. 2008).

This chapter introduces the topic of endometrial cancer and considers the disease in the context of worldwide incidence and disease burden. The diagnosis and current treatment recommendations are described, together with details of the development of laparoscopic hysterectomy and the political framework in which services for women with endometrial cancer are delivered in England.

2.2 The Endometrium

The uterus, or womb, is a pear shaped hollow organ designed to nourish and protect a fertilised egg. It is located in the female pelvis in front of the rectum and behind the bladder (Hughes 2009). It is made up of two distinct parts: the cervix or neck, also known as the cervix uteri and the body or corpus uteri (Figure 2.1).
Figure 2.1: The body of the uterus and cervix (Cancer Research UK (CRUK) 2009a online).

Although the cervix forms part of the uterus, in the study and treatment of cancer the cervix is considered separately and a clear distinction is made between cancer of the cervix (cervical cancer) and cancer of the body of the uterus (uterine cancer) (Benedet et al. 2000; Cancer Research UK (CRUK) 2009b online; Office for National Statistics (ONS) 2008a online; Winter & Gosewehr 2006 online).

The body of the uterus is made up of discrete layers of tissue and it is in the endometrium, the highly active epithelial lining, where about 90% to 95% of uterine cancers originate (Bakkum-Gamez et al. 2008; Winter & Gosewehr 2006 online) (Figure 2.1). Uterine cancer, therefore, most commonly refers to cancer of the endometrium (Benedet et al. 2000; CRUK 2009a online; Quinn et al. 2001). However, data collection of endometrial cancer incidence has traditionally included all types of uterine cancer because of the limitations of cancer data collection.

2.3 Cancer Data Collection

About half of the countries worldwide collect cancer registration data and there are concerns about the quality of that data because collecting information on cancer incidence can be difficult in countries where healthcare is not highly organised or
where resources are limited (Bilibrium & Winchester 2008). However, the International Agency for Research on Cancer (IARC), part of the World Health Organization (WHO), collects and interprets available worldwide cancer registration and mortality data. Data are coded according to the International Classification of Disease (ICD) which is periodically updated to reflect changes in medical knowledge. The current version, ICD-10, was agreed in 1990 and came into use in 1994 (World Health Organization (WHO) 2005). Cervical and uterine cancer have separate codes, as does cancer of the uterus, part unspecified (World Health Organization (WHO) 2007 online). Although only a small number of cases are coded as part unspecified, the need to have a code which represents a lack of detailed information, illustrates the difficulty in obtaining accurate data. The ICD-10 coding now also includes a subset for endometrial cancer and since 2006, it has been possible to obtain specific data regarding cancer of the endometrium (World Health Organization (WHO) 2007 online). However, to date, no international data sets have been published using this information.

Although the cellular origin of a cancer is important in treatment and research, guidelines are written to represent the most common incidences and so the International Federation of Gynecology and Obstetrics (FIGO) management of uterine cancer is essentially the management of endometrial cancer (Benedet et al. 2000). Publications on uterine cancer are often reporting on endometrial cancer and use the terms interchangeably (Benedet et al. 2000; Boyle & Levin 2008; Bray et al. 2005; Gatta et al. 1998).

This study concentrated on endometrial cancer as the most common form of uterine cancer but when discussing national and international cancer statistics prior to 2006, it was necessary to quote figures for uterine cancer.
2.4 Disease Burden

The GLOBOCAN 2002 database holds the most up-to-date estimates for worldwide cancer incidence and mortality available at the IARC. Data covers entire populations or samples selected from regions (International Agency for Research on Cancer (IARC) 2009 online).

2.4.1 Incidence

Globally in 2002, breast was the most common site for cancer in women and cervical was the most common gynaecological cancer. There were an estimated 198,783 new cases of uterine cancer (Parkin et al. 2005) (Figure 2.2).

Figure 2.2: World incidence of the 10 main cancers in women for 2002. Data shown in thousands for developing and developed countries by cancer site (Parkin et al. 2005)

However, uterine cancer was more common in Western industrialised nations with the highest incidence in North America and Western Europe and the lowest in the developing countries of South-Central Asia and Western Africa (Parkin et al. 2005) (Figure 2.3).
Figure 2.3: World age-standardised incidence and mortality rates of uterine cancer for 2002, selected regions (Cancer Research UK (CRUK) 2009a online). NB: Incidence rates are often expressed as age-standardised which represents an approximation of the average risk of developing endometrial cancer in a year and is used for comparisons between countries or populations over time (Parkin et al. 2005).

In North America the risk of developing uterine cancer is estimated at 23.3 per 100,000 females (National Cancer Institute (NCI) 2009a online) and in Europe it is 17 per 100,000 (Cancer Research UK (CRUK) 2009a online). The United Kingdom (UK) rates are amongst the lowest in Europe (Figure 2.4).
Although the age-standardised rate is widely used to account for age differences between populations (Figure 2.3), the underlying hysterectomy rate is not considered (Bray et al. 2005; Farley et al. 2007). Women who have had a hysterectomy are no longer able to develop endometrial cancer and should be removed from the population considered to be at risk. However, worldwide hysterectomy rates are not easy to obtain (Farley et al. 2007) and are rarely accounted for; by the age of 60 years, 20% of women in the UK and 37% in the United States (US) have had a hysterectomy (Gupta & Manyonda 2006). This rate has been as high as 50% in the US (Sutton 1997) and even in developing countries almost 20% of women have had a hysterectomy by the age of 55 years (Domingo & Pellicer 2009). Therefore, the true risk of developing endometrial cancer for women who have not had a hysterectomy could be higher.
In England in 2006, uterine cancer was the most common gynaecological cancer, with 5648 new cases, of these 96% (5463) were sub-coded as endometrium and published for the first time by the Office for National Statistics (ONS) (2008a online).

2.4.2 Mortality

Globally, an estimated 50,327 women died from uterine cancer in 2002 (Parkin et al. 2005) and in England and Wales, 1039 women died from the disease in 2006, 98% (1019) from cancer of the endometrium (Office for National Statistics (ONS) 2008b online). Cancer survival is measured by the number of people alive following the diagnosis and overall survival represents those alive more than five years later, those considered cured of the disease (National Cancer Institute (NCI) 2009b online). Disease-free survival is becoming increasingly important as a cancer survival measure, both for reducing the time taken to report on research (Sargent et al. 2005) and because of the increasing effectiveness of treatments to slow down metastatic or recurrent disease. It is now possible for people with cancer to be alive five years after diagnosis but still having treatment to control the cancer or symptoms, by current definitions they can be counted as overall survivors but this is not disease-free survival and would not be considered a cure.

The five year disease-free survival rate for uterine cancer is high; 82% of women in the developed world and 67% in the developing world will be considered cured of the disease following treatment (Parkin et al. 2005). In Europe, survival figures averaged at 76% for the years 1995-1999 (Sant et al. 2009) and figures for 2000-2004 in England, demonstrated a 77% survival rate (Office for National Statistics (ONS) 2005 online).
Although the incidence of uterine cancer is lower in developing countries, the mortality rates are higher (Cancer Research UK (CRUK) 2009a online; Parkin et al. 2005). Cancer mortality is generally higher in lower socioeconomic groups, this difference has not been widely studied but is often attributed to access to adequate healthcare (Kogevinas et al. 1997; Boyle & Levin 2008). Outcome disparity has also been identified within developed countries for women in low socioeconomic and ethnic groups (Allard & Maxwell 2009; Coleman et al. 2004; Farley et al. 2007; Yap & Roland 2006). In 2000, Michel Coleman et al. (2004) calculated a 3.6% gap in survival for women with uterine cancer in affluent compared to deprived areas of England and Wales. and the Cancer Inequalities in London report (Thames Cancer Registry 2007) showed higher mortality rates from uterine cancer in areas of most social deprivation.

In the US in 2006, non-Hispanic white women had the highest incidence of uterine cancer but comparable mortality rates were almost double in black women, resulting in survival rates of almost 61% for black women and over 84% for white women (Yap & Roland 2006). A higher incidence of more aggressive tumour types, later presentation, cultural and social barriers to healthcare advice, hormone use, hysterectomy rates, co-morbidity and genetic make-up, are cited as contributing to higher mortality rates in the black population, as well as access to healthcare insurance (Farley et al. 2007; Yap & Roland 2006).

### 2.5 Causes

The exact cause of endometrial cancer is unknown but 91% to 93% of cases occur in women over the age of 50 years (Cancer Research UK (CRUK) 2009a online; Parkin et al. 2005) and it is associated with diabetes, hypertension and continuous or prolonged exposure to the female hormone oestrogen in the absence
of sufficient levels of progesterone. This hormonal picture is seen with obesity, early
menarche and late menopause, menstrual cycles without ovulation, few or no full
term pregnancies and unopposed exogenous estrogens, for example, Hormone
Replacement Therapy (HRT) without progesterone (Boyle & Levin 2008; Bray et al.

2.5.1 Age

Cancer is a major condition of old age and increases in the number of people
reaching the seventh and eight decade of life has shown a corresponding increase
in the number of people affected by the disease (Boyle & Levin 2008). Over the past
50 years, life expectancy has improved all over the world but there is still significant
disparity in world regions and individual countries. The highest life expectancy for
women is 86.6 years in Andorra and the lowest is 39.8 years for women in
Swaziland (Boyle & Levin 2008). Women in the UK have a life expectancy of around
81 years (World Health Organization (WHO) 2008) but most babies born since the
year 2000 can expect to celebrate their 100th birthday (Christensen et al. 2009).

Endometrial cancer is relatively rare in women under 50 years of age and the
highest incidence is reached after 65 years (Boyle & Levin 2008; Cancer Research
UK (CRUK) 2009a online). Higher life expectancy in Western industrialised nations
means that women reach an age at which endometrial cancer becomes a significant
risk. Even countries in sub-Saharan Africa, which have some of the lowest life
expectancies, are predicted to see a 93% increase in the number of people aged
over 65 years between 2000 and 2020 (World Health Organization (WHO) Regional
Office for Africa 2009). Based upon life expectancy alone, endometrial cancer rates
are likely to continue to marginally increase in the developed world but significantly
increase in the developing world.
2.5.2 Obesity

Obesity is the most important risk factor for endometrial cancer. It is estimated to account for about 40% of the incidence and there is sufficient evidence to suggest a causal link (Boyle & Levin 2008). Obesity is measured by Body Mass Index (BMI) (an index of height for weight), where 25-30 is defined as overweight and pre-obese, 30-35 class I obesity, 35-40 class II and over 40 is defined as severely obese or class III, sometimes referred to as morbid obesity (World Health Organization (WHO) 2009). Obese women have a two to threefold increased risk of developing endometrial cancer and there are concerns regarding the continued rise in obesity leading to a continued rise in the number of women presenting with the disease (Bakkum-Gamez et al. 2008; Calle & Kaaks 2004; Calle & Thun 2004; Kaaks et al. 2002).

The mechanism by which obesity increases the risk of endometrial cancer is not fully understood but it is primarily due to oestrogen (Boyle & Levin 2008; Calle & Kaaks 2004; Calle & Thun 2004). Most endometrial cancers are endometrioid adenocarcinomas, which is the histological sub-type most sensitive to oestrogen stimulation (Emons et al. 2000; Yap & Roland 2006). In women before the menopause, obesity leads to menstrual cycles that do not include ovulation and continuous oestrogen stimulation of the endometrium. In women after the menopause, increased body fat increases the concentration of endogenous oestrogens (Bakkum-Gamez et al. 2008; Calle & Kaaks 2004). Obesity also causes tissues to become insensitive to insulin which increases insulin levels and is thought to stimulate the cell proliferation required for cancer development (Calle & Kaaks 2004). Type II diabetes and hypertension are also independent factors associated with endometrial cancer and obesity (Boyle & Levin 2008).
Lower rates of endometrial cancer are seen in countries where there are lower rates of obesity, for example, in Japan 3% of the population are obese compared to 40% the US where there is a seven times higher prevalence of the disease (Bakkum-Gamez et al. 2008; Kuriyama et al. 2005). However, obesity is increasing in most developed countries as well as in urban areas of developing countries (Benedet et al. 2000; Boyle & Levin 2008; Bray et al. 2005; Calle & Kaaks 2004) and overeating is seen as the largest avoidable cause of cancer in non-smokers (Calle & Thun 2004; Renehan et al. 2008). Low rates of physical activity leads to an increased risk of obesity but reduced physical activity is also an independent risk factor for endometrial cancer (Farley et al. 2007).

2.6 Trends

Although cancer data sources are continually improving in quality and estimates may not be truly comparable over time (International Agency for Research on Cancer (IARC) 2009), the overall incidence of cancer appears to be rising (Boyle & Levin 2008). In 1997 the IARC estimated an increase in cancer cases to 2010 by, 27% in Europe, 44% in North America, 68% in Japan, 92% in Asia, 101% in South America and 116% in Africa.

The WHO also reports that the incidence of endometrial cancer is rising (Boyle & Levin 2008). There is a general trend showing an increase incidence in women in Europe (Bray et al. 2005) and there was a 25% increase in England and Wales from 1990 to 2001 (Cooper et al. 2008). Projected cancer mortality rates in the UK for the years 2006-2025 were estimated by CRUK and the only predicted cancer increase in women was 18% for uterine cancer (Olsen et al. 2008).

Endometrial cancer trends in the US remain difficult to interpret because of what Persky et al. (1990:935) described as ‘striking increases’ in the early 1970s as a
result of the extensive use of oestrogen based HRT without progesterone for menopausal and postmenopausal women. The decline in incidence that followed the introduction of progesterone, to oppose the oestrogen and protect the endometrium, continues to have an effect on trend data. However, even in the US, the incidence of endometrial cancer is rising (Bakkum-Gamez et al. 2008).

Although uterine cancer data can be difficult to obtain and variation across and within populations adds to the complexity, there is little doubt that endometrial cancer rates will increase, primarily due to aging populations and the universal adoption of unhealthy lifestyles, especially the use of highly calorific food and reduction of physical activity (Boyle & Levin 2008).

2.7 Presentation

Women with endometrial cancer most commonly present with vaginal bleeding after the menopause (Department of Health (DH) 1999). This symptom tends to appear early in disease development and 10% of women with postmenopausal bleeding will have endometrial cancer (Bakkum-Gamez et al. 2008).

In developing countries women are more likely to present with late stage disease which is thought to contribute to higher mortality rates than those seen in developed countries (Coleman et al. 2001; Madison et al. 2004). Even in developed countries late presentation of cancer is a concern and is thought to contribute to the relatively poor survival rates seen in the UK against comparable European countries (Sant et al. 2009; Richards 2009). The trend for earlier diagnosis of endometrial cancer in developed countries would suggest that postmenopausal bleeding acts as a trigger for women to present to a healthcare provider. Although bleeding is not a well recognised symptom of cancer (Robb et al. 2009), the return of vaginal bleeding for postmenopausal women is inconvenient and costly with regard to the purchase of
sanitary protection, which may be drivers for seeking early advice. The classic teaching in gynaecology is that 'postmenopausal bleeding represents endometrial cancer until proven otherwise' and this was written into National Health Service (NHS) cancer standards where post menopausal bleeding triggers the urgent suspected cancer referral pathway to ensure rapid diagnosis and treatment (Department of Health (DH) 1999; National Cancer Action Team 2008).

2.8 Treatment

Cancer treatments primarily involve surgery, chemotherapy and/or radiotherapy to remove or destroy the primary cancer and any possible spread. Defining the extent of disease in cancer is referred to as staging and is usually based upon the size of a primary tumour, whether lymph nodes contain cancer and whether the cancer has spread from the original site to other parts of the body (National Cancer Institute (NCI) 2009b online). The grade of a tumour is also considered; the more abnormal or less well-developed a cancer cell is, the higher the grade (CRUK 2008a online); grade one being more like normal cells and grade three representing the most abnormal. Cancer treatments are largely based upon the stage and grade of the disease (Cancer Research UK (CRUK) 2008a online).

2.8.1 Surgery

Surgery has been used to treat cancer since at least 1700 BCE (Lee 2000). There are references to removal of the uterus in the early ages which would have been removed through the vagina, primarily for obstetric problems and uterine prolapse (decent of the uterus into the vagina) (Benrubbi 1988). In the year 1670 Faith Howard is reported to have cut off her own uterus when it prolapsed through the vagina as she lifted bags of coal (Sutton 2001).
The first reported surgical opening of the abdomen was in the year 1809 and the first abdominal hysterectomy was performed in 1843, although it was 10 years before a woman would survive the procedure (Sutton 1997). Early abdominal hysterectomies were sub-total, removing the body of the uterus but leaving the cervix behind and the procedure was performed using a vertical or midline incision. The rates of wound dehiscence and hernia were reduced with the use of the transverse incision in 1900 and in 1929 the first total abdominal hysterectomy (TAH) was performed; removing the whole of the uterus including the cervix, in order to reduce postoperative vaginal discharge and the risk of developing cervical cancer (Sutton 1997).

In cancer surgery, a Greek physician in the year 502 is reported to have advocated cutting back to healthy tissue when excising a tumour and the surgeon Guy de Chauliac (1298-1370) recommended a wide excision to treat cancer (Lee 2000). Wide excision, which includes the removal of a specified amount of normal tissue and possibly the draining lymph nodes, is often referred to as radical surgery. The first radical hysterectomy for uterine cancer was described in the year 1895 (Benrubí 1988; Lee 2000).

2.8.1.1 Abdominal Hysterectomy

The current recommended procedure to stage and treat the majority of women with endometrial cancer is to remove the entire uterus (a total hysterectomy) together with both fallopian tubes and ovaries (bilateral salpingo-oophorectomy) using a vertical or midline incision in the abdomen (Bakkum-Gamez et al. 2008; Benedet et al. 2000; Department of Health (DH) 1999). The vertical incision is recommended to maximally open the abdomen allowing the surgeon to observe the pelvis, abdomen and intra-abdominal contents including the omentum, liver,
peritoneal cul-de-sac and adnexal surfaces (Benedet et al. 2000). Opening the abdominal cavity with an incision is sometimes called a laparotomy or referred to as open surgery.

Extended or radical hysterectomy is not usually required to obtain a wide excision in endometrial cancer because of the early stage at presentation, which means that the cancer is confined to the endometrium with little spread into the uterus or onto the cervix and healthy tissue around the cancer can be removed without extended dissection (Benedet et al. 2000). Removal of the ovaries is recommended to reduce the risk of hormonal activity on any remaining abnormal cells and to diagnose and treat any concomitant ovarian cancer which is recognised in about 5% of all cases of endometrial cancer (Guzin et al. 2006).

A sample of abdominal fluid (peritoneal washings) should be taken at the time of surgery and any decision about removing the draining lymph nodes (lymphadenectomy) made depending upon the degree of risk of cancer spread (metastasis) (Benedet et al. 2000). However, removal of lymph nodes in women with endometrial cancer is controversial following the results of the Medical Research Council (MRC) ASTEC trial (A Study in the Treatment of Endometrial Cancer) which reported lower survival rates in women who underwent lymphadenectomy compared to those who had hysterectomy alone (ASTEC Study Group 2009).

Removing the uterus through the vagina does not facilitate visual inspection of the internal pelvic and abdominal structures and surfaces, or allow for washings to be taken as required to adequately assess the disease. Therefore, vaginal hysterectomy alone is not a recommended route to perform hysterectomy for cancer of the endometrium (Benedet et al. 2000). However, vaginal hysterectomy is a less morbid procedure (Nieboer et al. 2009 online) and there is increasing interest in its
use in endometrial cancer for high risk surgical groups such as the elderly or medically compromised (Scribner et al. 2001; Susini et al. 2005).

2.8.1.2 Laparoscopic Hysterectomy

The uterus can now be removed using an endoscope which is an instrument used to examine the interior of the body. The earliest references to endoscopy date back to Hippocrates (460-375 BCE) where there is a description of an examination of the rectum using a speculum (Mount Sinai Medical Centre 2009 online). The key to viewing inside a body cavity lies in the ability to introduce light to visualise internal structures and surfaces. Endoscopes are given specific names relating to the part of the body that is accessed, for example, colonoscopy for viewing the colon and bronchoscopy for viewing the main airways of the lungs via the bronchus.

Laparoscopy comes from two Greek words, lapara, meaning the soft parts of the body between rib margins and hips and skopein, to see, view or examine (MedTerms 2004 online). Therefore, laparoscopy is concerned with viewing the internal organs and surfaces of the abdomen and pelvis. The first experimental laparoscopy was performed on a dog in 1901 in Germany (Mount Sinai Medical Centre 2009 online). A small incision in the abdomen or pelvis allows the endoscope to be introduced into the cavity to give a clear view of the internal organs. Laparoscopy became an important diagnostic tool in gynaecology following its use by Patrick Steptoe, famous for his fertility treatments in the late 1960s (Sutton 1997).

As endoscopic technology has developed, the instruments required for performing surgical procedures, such as scissors and cutting devices, suturing and cautery equipment, can be introduced into the cavity alongside the laparoscope. Laparoscopic surgery is often referred to as 'keyhole' surgery. Initially the surgeon would view the cavity by looking directly into the scoping equipment but the
The development of small silicone chip cameras has enabled the operating team to view the procedure on a television screen (Sutton 1997).

When Reich et al. (1989) reported the first laparoscopic hysterectomy (see Box 2.1 For a description of the surgery), gynaecologists were quick to adopt the new technique, which was performed entirely using the laparoscope; a Total Laparoscopic Hysterectomy (TLH). However, other gynaecologists felt this took too long and performed part of the procedure vaginally, which became known as a Laparoscopically Assisted Vaginal Hysterectomy (LAVH) (Ghezzi et al. 2006).

The specific components of the surgery recommended to adequately stage and treat endometrial cancer (hysterectomy, salpingo-oophorectomy, good visual assessment of the pelvis and abdomen, peritoneal washings and lymphadenectomy when required) are all now possible using a laparoscope, as first demonstrated by Childers et al. in 1993.

Interest in laparoscopic surgery has been driven by surgeons based upon the perceived advantages of reducing injury to the external part of the body. It follows the belief that it is the incision which causes the

**Box 2.1 Description of laparoscopic surgery for endometrial cancer.**

The procedure is usually carried out under general anaesthesia. Intravenous fluids are administered and a catheter is placed in the bladder. A manipulator is placed in the vagina. The laparoscope is inserted into a 2-3mm incision below the umbilicus and two or three further incisions are made in the lower abdomen. These incisions are ports or sites of entry for the operating equipment and a trocar is used to puncture the body cavity before the instruments are passed into the cavity. Carbon dioxide gas is used to inflate the abdomen and create a space for the surgeon to work and have a clear view of the abdomen and pelvis.

The uterus is freed from the ligaments and supporting structures and removed through an incision in the vagina. Both tubes and ovaries are removed together with the lymph nodes if appropriate. The pelvic cavity is washed out with a sterile solution. As much gas as possible is removed. The vaginal and abdominal incisions are closed with sutures, commonly dissolvable (especially in the vagina).
most potential for harm; without the incision the surgery becomes ‘minimally invasive’ to the patient. However, abdominal incision was not the only risk to patients undergoing early surgical procedures. Surgical mortality has dramatically reduced over the centuries with improvements in anaesthesia, suture and cautery equipment, antiseptics and aseptic techniques and antibiotics; it has never been safer to have any operation (Watcher 2008). Physical harm is no longer the overriding issue surrounding surgical techniques and the decision to perform one procedure over another may rely on the personal preference of the surgeon or the patient.

Not all gynaecological surgeons perform laparoscopic hysterectomy (Domingo & Pellicer 2009; Frumovitz et al. 2004, Mabrouk et al. 2009) and as a consequence, not all women with endometrial cancer will have access to this type of surgery, as highlighted in the Service Development Project presented in Chapter 13. Women with late stage disease and those at greater risk of recurrence after surgery will require other forms of treatment, or adjuvant therapy.

2.8.2 Adjuvant Therapy

Radiotherapy and chemotherapy are both used in the treatment of cancer. Ionizing radiation has been used to damage cellular DNA since it was discovered at the end of the 19th century (Connell & Hellman 2009) and chemotherapy is the broad term used to describe the use of chemicals in the treatment of disease but which primarily involves the use of cytotoxic agents that target and destroy cancer cells (DeVita & Chu 2008).

In endometrial cancer, chemotherapy and/or radiotherapy are recommended if the disease has spread beyond the uterus or more than half way through the muscle wall or if there is a high risk cell type present (such as grade three) (Benedet et al.
2000; Department of Health (DH) 1999). Following surgery, high-risk disease is thought to be present in about 19.2% of cases (Lee et al. 2006). However, the ASTEC study showed no improved survival for women having postoperative radiotherapy (ASTEC/EN5 Study Group 2009).

2.9 Patient Choice

According to the National Health Service Constitution:

'you have the right to make choices about your NHS care and to information to support these choices' (Department of Health (DH) 2009a:7).

Patient choice is a key priority for governments in the UK but one of the key issues in cancer care is improving survival: in England, The NHS Plan (Department of Health (DH) 2000a) promised greater patient choice but The NHS Cancer Plan (Department of Health (DH) 2000b) made no reference to patient choice, concentrating instead on equal access to high quality, standardised services.

2.9.1 Co-ordination of Cancer Services

Since the publication of the first EUROcare study (Berrino et al. 1995) highlighted the relatively poor cancer survival figures for the UK, in relation to comparable countries in Europe, there has been government pressure to improve cancer services and cancer outcomes (Richards 2009 online).

Significant changes to gynaecological cancer services followed the report from the Chief Medical Officers of England and Wales, known as the Calman-Hine report (Department of Health (DH) 1995) and the publication of Improving Outcomes Guidance (IOG) (Department of Health (DH) 1999). These changes involved service restructure and regulation to ensure equal access to high quality cancer services for all National Health Service (NHS) patients. For women with suspected endometrial
cancer, a defined pathway was established; investigation in a designated cancer unit and definitive treatment in a cancer unit or cancer centre according to the grade and stage of the disease (Department of Health (DH) 1999), as discussed in the Policy Review presented in Chapter 12. All cancer services in England have been reorganised in the ensuing 20 years and, in 2009, the service comprises 28 Cancer Networks monitored and assessed by a system of Peer Review to a set of prescriptive minimum standards (National Cancer Action Team 2008). This centralised model of cancer care runs alongside but is distinct from the patient choice agenda.

2.9.2 Choice in Cancer

The patient choice agenda has focused primarily on choice of providers; The NHS Plan (Department of Health (DH) 2000a) promised a choice of General Practitioner (GP), choice of hospital clinic, choice of appointment and the NHS Next Stage Review (Darzi 2008) considers empowerment that comes from having choice in the system. However, cancer services are exempt from this level of choice in the NHS Constitution (Department of Health (DH) 2009a). The Cancer Reform Strategy (CRS) (Department of Health (DH) 2007) aimed to build on progress made since The NHS Cancer Plan (Department of Health (DH) 2000b) and set the direction for cancer services to the year 2012. The CRS considered patient choice in the context of delivering cancer services but did not go on to explain how patient choice can be achieved, especially when the report promises to strengthen agreed clinical guidelines and pathways which by their very nature limit choice through standardisation. The first annual review of the CRS under the heading 'improving quality and choice', reported on better information enhancing choice but concentrated the data collection roles of the National Cancer Intelligence Network (NCIN) and the Multi-Disciplinary Teams (MDTs) (Department of Health (DH) 2008).
The second annual report did not cover choice as a discrete topic (Department of Health (DH) 2009e).

According to the British Attitude Survey in 2007, not only do the public feel that patients should have a choice of hospital and appointment but 71% said patients should have a choice of treatment (Park et al. 2009). Although choice of treatment was important for the public, it seemed more difficult to deliver for policy makers. Lord Darzi in *The NHS Next Stage Review* (Darzi 2008:10) promised that the NHS Constitution would include ‘rights to choose both treatments and providers’ but the NHS Constitution fails to mention treatment choices in favour of ‘choices about (your) NHS care’ (Department of Health (DH) 2009a:7). However, those surveyed were randomly selected British Citizens, who may, or may not, have experienced ill health or healthcare services.

For individuals with cancer there are opposing views about treatment choice; some patients want treatment choices (Jenkins et al. 2001; Luker et al. 1996; van Tol-Geerdink et al. 2006) while others find choice in a life threatening situation increases anxiety and uncertainty, preferring a passive role in decision making (Elkin et al. 2007; Leydon et al. 2000). It would seem that choice of treatment is a difficult concept in healthcare in general and choice of treatment and choice of services are difficult in cancer care.

However, the key theme running through both the patient choice agenda and improvements in cancer services is information. Access to information appears in *The NHS Constitution* (Department of Health (DH) 2009a) and the CRS (Department of Health (DH) 2007:105) suggests that ‘high quality information will: empower patients in making important decisions about their care’. However, information and choice are not always dependent and satisfaction with the level of
information given has been shown to be more likely to lead to satisfaction with services than being offered choice (Fallowfield et al. 1994; Fallowfield 2001; Jenkins et al. 2001).

2.10 Patient Experience

Understanding the patient experience is also considered a priority in improving services in the NHS and cancer was included as a condition in the regular surveys of patients and users proposed in the White Paper, *The new NHS: modern, dependable* (Department of Health (DH) 1997). The CRS states that 'we need to collect and use high quality data on patients’ experience on treatment and care’ (Department of Health (DH) 2007:105). In order to understand the patient experience it is necessary to not only understand the disease but also the illness, that is, how the individual experiences the disease (Radley 1994). Although cancer is often considered as one condition, it actually includes over 200 different types (Cancer Research UK (CRUK) 2008b online) and the cancer patient baseline survey included just six cancers with 39% of responses coming from breast cancer patients on a range of predefined topics (Department of Health (DH) 2002). The experience of women with endometrial cancer will be significantly different from other cancers, and having surgery different from having radiotherapy or chemotherapy.

Government strategy continues to support concepts of providing more holistic care in keeping with patient feelings, ideas, functioning and expectations (Department of Health (DH) 2007). However, this can only be done through the involvement of patients and in developing services and research aimed at understanding the experience in all aspects of care and not just perception of need before becoming ill or the views of specific groups on predefined issues.
2.11 Summary of Chapter

Endometrial cancer is a common cancer which is more prevalent in industrialised nations in the West because of its association with older age and obesity. However, the incidence of the disease is increasing across the world. It is generally diagnosed as Stage I and treatment in the form of surgery is likely to be curative. Developments in laparoscopic surgical techniques mean that women with endometrial cancer are increasingly being treated with this type of surgery, where there is a surgeon to perform the procedure. As a result of the relatively poor survival rates of people with cancer in the England, the development of Cancer Networks and Peer Review have regulated cancer services, which limits choice for women with endometrial cancer. Choice is a complex concept in cancer which may be difficult to deliver or what cancer patients want. Understanding the patient experience is a key feature to delivering services which are responsive to patient need.
CHAPTER 3: LITERATURE REVIEW

3.1 Introduction

This chapter provides an overview of the literature regarding the use of the laparoscope in endometrial cancer surgery. It forms one part of the review of the literature in this study and the reasons for this will be discussed, together with a synopsis of the four themes identified: safety and efficacy, complications, cost, and quality of life. The purpose of this literature review was to provide background information on the surgical technique with which to focus the study and prepare for NHS ethical review.

3.2 The Role of the Literature Review

The literature review has a different role depending upon the type of research approach used to conduct a study (Burns & Grove 2006). It has traditionally formed an initial step in the research process, providing the researcher with a comprehensive background to understand current knowledge and identify gaps which will define the research question or hypothesis (Cronin et al. 2008). However, this study used phenomenology to explore the experience of women who had undergone laparoscopic surgery and a detailed description of the methodology and why it was chosen is described in Chapter 4.

In phenomenology the value of a pre-study literature review is debated, with some researchers suggesting that data should be analysed first and the findings then interpreted in the context of what is known (Streubert Speziale 2007a). The primary reason cited for not conducting an initial literature review, is to protect the researcher from presupposition and bias, which may result in leading participants to discuss issues they would not have otherwise considered part of their experience.
(Burns & Grove 2006; Munhall 2007; Streubert Speziale 2007a). However, some qualitative researchers accept that an initial review of the literature may help focus the study (Carpenter 2007a; Munhall 2007; Streubert Speziale 2007a) and others suggest that exploring the literature is part of the exploration of bias and assumptions, required as part of the research process (Morse & Field 1996; Lowes & Prowse 2001).

Healthcare research often involves the study of vulnerable groups and/or individuals at a vulnerable time. Carrying out a pre-study literature review can guide and focus the development of a study but it can also ensure compliance with Good Clinical Practice (GCP), as described below.

3.2.1 Good Clinical Practice

This study involved participants who were approached and recruited as a result of treatment in the NHS. The Declaration of Helsinki provides a statement of ethical principles for medical research involving human subjects (World Medical Association 2008 online) and although this study does not involve the use of pharmaceutical products, it is required by the NHS to comply with regulations based upon the International Conference on Harmonisation of Technical Requirements on Registration of Pharmaceuticals for Human Use (ICH) Good Clinical Practice (GCP) (International Conference on Harmonisation of Technical Requirements on Registration of Pharmaceuticals for Human Use (ICH) 1996 online). This standard of good practice is embedded into European law and requires that all trials involving human subjects and medicinal products are subject to ethical review and approval (European Parliament 2001 online; European Parliament 2005 online).

In the NHS, all research studies involving patients or staff are submitted for ethical approval to a Research Ethics Committee (REC) under the guidance and
legal responsibility of the National Research Ethics Service (NRES) (National
Patient Safety Agency 2009 online). As part of this process, research study
protocols should provide a summary of the known and potential risks and benefits to
participants, a summary of the findings from other studies and data on the
background of the trial (International Conference on Harmonisation of Technical
Requirements on Registration of Pharmaceuticals for Human Use (ICH) 1996
online).

Conducting a pre-study literature review ensured that NHS patients were
entering a safe study that had not already been conducted and that this could be
comprehensively relayed to an ethics committee (Chapter 5). This type of surgery
has only been performed since 1988 and all the literature referring to the procedure
was searched to develop an understanding of the key themes. The potential for bias
casted by this approach in a phenomenological study is explored in Chapter 4.

3.2.2 The Second Part of the Literature Review

The second part of the literature review was carried out during data analysis as
themes emerged and were explored in the literature. The literature was used to
reflect, contrast or refute the analysis to develop a deeper understanding of the
phenomenon by enriching and broadening its scope from other perspectives and
disciplines, as described by Munhall (2007). This integration (or synthesis) of
findings, interpretation and the literature, is presented in Chapter 8. The remainder
of this chapter will present the findings of the pre-study literature review.

3.3 Literature Search

To retrieve relevant literature, electronic searches were conducted in the
following databases: PubMed, MEDLINE, EMBASE, PsychINFO, Health
Management Information Consortium, British Nursing Index, Cumulated Index of
A search of the Internet was also undertaken using Google. The initial search was carried out at the end of 2006 and was not formally limited to a publication year because it was anticipated that there would be few relevant publications prior to 1988. Repeated searches for 'laparoscopic hysterectomy' were carried out through to December 2009, to ensure updated information was included in the report. Laparoscopic surgery is performed all over the world and articles in all languages were considered where there was an abstract in English or where the authors were referenced in leading papers. Search terms centered around the use of the key words laparoscopy/ laparoscopic/ 'keyhole' and 'minimally invasive' in relation to surgery and cancer/ carcinoma/ oncology/ neoplasm or hysterectomy with or without cancer/ carcinoma/ oncology/ neoplasm. These terms developed as articles were screened and an understanding of the language used by researchers in the field was established.

The titles and abstracts of all articles from the database search were screened to exclude those not relevant to the study. Relevant articles were retrieved and read in full. The reference lists of articles reviewed were also searched for relevant publications.

On reviewing the published papers regarding the use of laparoscopic surgery in endometrial cancer four key themes emerged: safety and efficacy, complications, cost and quality of life. These themes reflected research questions posed primarily by medical researchers and evidence of research from a nursing care perspective or based upon patient experience, was absent in the literature. Since abdominal hysterectomy is an established, effective treatment, a significant proportion of the studies compared laparoscopic hysterectomy with abdominal or open hysterectomy. Each theme will be presented individually.
3.4 Safety and Efficacy

Performing a surgical procedure for cancer not only removes the tumour but also attempts to remove any microscopic cancer spread which could lead to disease recurrence (Donohue 2001). Illness, injury or incapacity is referred to as morbidity (Oxford English Dictionary (OED) 2009 online) and treatments for cancer also have the potential to cause morbidity, whether or not the cancer is cured. When assessing the safety and efficacy of a new cancer treatment, success is measured in survival and morbidity, in the short and long-term. Short-term would include the immediate safety of the treatment, that is, death or injury during the operation or in the immediate postoperative period. ‘Short-term’ can also refer to the first few months or years following treatment but should be reserved to describe the first five years. This would then leave the phrase ‘long-term’ to describe five years and beyond, which would be in keeping with cancer survival data, as discussed in Chapter 2. However, there was little consistency in the laparoscopic hysterectomy literature with the use of the phrases ‘short-term’ and ‘long-term’. The reports have, therefore, been interpreted in keeping with cancer survival definitions.

3.4.1 In Endometrial Cancer

Endometrial cancer has been successfully treated with surgery for many years and the introduction of a new surgical technique has the potential to compromise already high levels of safety and efficacy. Immediate safety issues are relatively easy to report as case studies but long-term follow-up is required to assess safety and efficacy from an overall cancer survival and long-term morbidity perspective. In these primarily surgical studies, efficacy is also measured in terms of comparable
surgical excisions, for example, the extent of dissection and the number of lymph nodes harvested during a lymphadenectomy (Tozzi et al. 2005a; Zullo et al. 2005).

The safety and efficacy of laparoscopic surgery with regard to cancer is still debated but there is increasing evidence that laparoscopic surgery in endometrial cancer is as safe and effective as abdominal hysterectomy, at least in the short-term (Ghezzi et al. 2006; Humphrey & Sachin 2009; Kim et al. 2005; Kuoppala et al. 2004; Magrina et al. 1999; Malur et al. 2001; Obermair et al. 2004; Querleu & Leblanc 2003; Schlaerth & Abu-Rustum 2006; Tozzi et al. 2005a; Walker et al. 2009; Zapico et al. 2005). This includes high-risk surgical patients such as those who are obese or elderly and those with co-morbidities such as diabetes (Eitabbakh et al. 2000; Ghezzi et al. 2006; Holub 2003; Holub et al. 2000; Humphrey & Sachin 2009; Langbebekke et al. 2002; Manolitsas & McCartney 2002; O’Hanlan et al. 2004; Willis et al. 2006 online; Yu et al. 2005). This is an important issue in endometrial cancer because these are the groups of women who have a higher likelihood of developing the disease, as discussed in Chapter 2.

However, laparoscopic hysterectomy remains a relatively new technique and long-term data are not yet available. There is also a lack of what is considered high-level medical evidence in the form of the Randomised Controlled Trial. Some studies report the results of randomised prospective trials (Malur et al. 2001; Tozzi et al. 2005a; Walker et al. 2009; Zapico et al. 2005; Zullo et al. 2005) but the majority of publications in this literature review were small retrospective studies reporting on laparoscopic surgery alone, such as Magrina et al. (1999), or where no randomisation occurred and selection bias for laparoscopic surgery was seen. For example, Kim et al. (2005) described patients undergoing laparoscopic surgery as receiving the ‘treatment of choice’ and the control group as patients who had
'abdominal surgery during the same period'. There was no explanation in this paper about the reasons for not performing the 'treatment of choice' in the control group. In two systematic reviews, Granado de la Orden et al. (2008) and Palomba et al. (2009) were only able to report on the same four randomised clinical trials, comparing the use of laparoscopic hysterectomy to open surgery in the treatment of endometrial cancer. However, in surgery, randomised trials, rather than retrospective reports, remain in the minority (Stirrat 2004). The National Cancer Research Network (NCRN) holds a database of high-quality nationally approved clinical studies in cancer and in October 2009 there were 18 gynaecological cancer studies open to recruitment on the NCRN website and only one was a surgical trial (United Kingdom Clinical Research Network (UKCRN) 2009 online).

In 2005, the Gynecological Oncology Group (GOG) in the US closed a large prospective Randomised Controlled Trial comparing open surgery to laparoscopic surgery in the management of uterine cancer. This was called the GOG LAP2 study and was set up because:

'Laparoscopic surgery is a less invasive type of surgery for cancer of the uterus and may have fewer side effects and improve recovery. It is not known whether laparoscopic surgery is more effective than standard surgery in treating endometrial cancer' (National Cancer Institute (NCI) 2009c).

Just over 2,600 women were recruited but it remains too early to determine recurrence rates and overall survival. The published findings suggest that laparoscopic surgery is as safe as laparotomy with similar rates of intraoperative injury and death within six weeks of surgery in both groups (Walker et al. 2009). Malzoni et al. (2009) have published some survival data past five years (range 2 to 81 months, median 38.5 months) but although the findings suggest similar results
for laparoscopic and open surgery, the authors warned that multicentre randomised trials with long-term follow-up are still required.

At this point it appears that, as a surgical procedure for endometrial cancer, laparoscopic hysterectomy presents no greater threat to patient safety than open surgery. The technique produces comparable samples of tissue but survival data for women five years post treatment remains limited. However, port-site metastasis emerged as a specific concern.

**3.4.2 Port-site Metastasis**

Safety concerns have been raised regarding port-site or trocar-site (the place where the laparoscope or instruments enter the abdomen) metastasis or recurrence with the use of the laparoscope in endometrial cancer (Abu-Rustum et al. 2004; Faught & Fung Kee Fung 1999; Kadar 1997; Maenpaa et al. 2009; Muntz et al. 1999; Sanjuan et al. 2005; Wang et al. 1997; Zivanovic et al. 2008). With the exceptions of Abu-Rustum et al. (2004) and Kadar (1997) who looked at a series of women with gynaecological malignancies and Zivanovic et al. (2008) who looked at a series of women with malignant disease, these have been individual case reports, making it difficult to assess the significance in relation to the general population of endometrial cancer patients. Zivanovic et al. (2008), in their prospective study, estimated the uterine cancer port-site metastasis rate to be very low at 0.18%. However, the true incidence and relevance of port-site metastasis in endometrial cancer remains unknown and there have also been case reports of laparotomy site recurrence in endometrial cancer (Curtis et al. 2004; Khallil et al. 1998).

There were no reports of port-site metastasis in any of the comparative laparoscopic surgery studies discussed in this literature review and so it has been assumed that the incidence is low (Obermair et al. 2004). The GOG LAP2 study was
amended partly to monitor port-site recurrences, which will hopefully lead to an accurate estimated rate when this trial reports on long-term data. Data so far, with the exception of a single case report (Muntz et al. 1999), support the view that port-site metastasis is almost always a sign of advanced disease, and should not be used as an argument against laparoscopic surgery in gynaecological malignancies (Obermair et al. 2004; Zivanovic et al. 2008).

3.5 Complications

Defining and reporting a complication is not straightforward and variation was seen throughout the literature. A complication, in this setting, could be seen as an additional problem that arises during or following the procedure (MedTerms 2004 online). However, Orbuch and Reich (2004) define surgical complications in laparoscopic hysterectomy as problems that remain unrecognised during surgery which result in postoperative sequelae or compromise the patient. Using this definition they report their complication rate as 2.7%, compared to 11.8% if they had considered problems corrected during the surgery. In a systematic review of complications associated with laparoscopic and open hysterectomy in benign disease, Meikle et al. (1997) comment on the lack of reporting of complications by authors in the studies reviewed. The complications that were listed ranged from intraoperative trauma to other organs and blood loss, to postoperative complications such as, pulmonary embolus, infection, wound breakdown, blood collections, pain, ileus, hernia, lower limb swelling and incontinence. There was little consistency with the defining, measuring or reporting of complications in the studies reviewed.

There were also other inconsistencies and variables that made understanding complications and complication rates difficult, such as, different type and extent of
laparoscopic hysterectomy, the use of different incisions and population differences between benign and malignant disease. These will be discussed individually.

### 3.5.1 Type and Extent of Laparoscopic Hysterectomy

Some surgeons perform Laparoscopically Assisted Vaginal Hysterectomies (LAVH) while others perform Total Laparoscopic Hysterectomy (TLH), as discussed in Chapter 2. There were a small number of studies which compared LAVH to TLH (Cheung & Rosenthal 2002; Ghezzi et al. 2006; Jin & Jang 2008; Nieboer et al. 2009) but the majority compared either LAVH or TLH to an abdominal or open procedure. There were also differences in the detail of the procedure dependent upon the operating surgeon, for example, in the use of cautery, stapling devices, different methods of dissection etc; as Meikle et al. (1997:309) pointed out ‘operating room situations are difficult to duplicate’. Also, when treating endometrial cancer, some women will have a lymphadenectomy while others will not. If a lymphadenectomy is performed as an additional procedure, the extent of the surgical dissection and the operating time are increased. Essentially, this means that laparoscopic hysterectomy is not a generic procedure and the complications and complication rates may differ even within the laparoscopic cohorts.

### 3.5.2 Surgical Incision

The FIGO guidelines for the treatment of endometrial cancer recommend that a vertical or midline incision is used in abdominal hysterectomy (Benedet et al. 2000) but the Department of Health (1999) does not stipulate the type of incision to be used because UK gynaecologists have been reluctant to use a vertical incision, even for endometrial cancer surgery. This was reflected in a protocol change in the ASTEC study, which initially recommended the use of a vertical incision but later allowed for surgeon discretion on a transverse incision, ostensibly for obese
patients. The surgical arm of the study reported 48% of surgeons who recorded the incision type, as using a transverse incision (ASTEC Study Group 2009). Although challenged for lack of evidence (Ellis et al. 1984), vertical incisions are generally associated with a higher complication rate, especially with regard to wound infection and postoperative mobility (Baker 2006).

Making comparisons between open surgery and laparoscopic surgery and complications like wound infection and hospital stay are difficult, if the type of incision used is not reported. Gemignani et al. (1999) and Malzoni et al. (2009) do refer to abdominal hysterectomy being carried out using a vertical incision and Langebrekke et al. (2002) refer to the use of a transverse incision but mostly the control groups were reported as having a laparotomy or abdominal hysterectomy without reference to the type of incision used to perform the procedure.

3.5.3 Benign Versus Malignant Disease

Laparoscopic hysterectomy was first performed in the benign setting and has moved into the cancer setting as it has developed (Childers et al. 1993). The research literature covers benign and malignant disease and some of the issues are relevant to both settings while others are not. Safety and efficacy have some specific concerns with regard to cancer but complications, cost and quality of life are considered more generic. However, age range, average BMI and the surgical incision used, generally differ in women having a hysterectomy for benign disease to those having a hysterectomy for cancer.

3.5.3.1 Age Differences

Hysterectomy for benign disease is rarely performed after the menopause but endometrial cancer is uncommon before the menopause, with the highest incidence after 65 years of age, as discussed in Chapter 2. In benign disease, the mean age
of women in the studies reviewed by Meikle et al. (1997) and the women studied by Garry et al. (2004) was 43 years, compared to Tozzi et al. (2005b) and Malur et al. (2001) in endometrial cancer, where the mean age was 67 years.

### 3.5.3.2 Body Mass Index (BMI)

The BMI of women who have a hysterectomy for endometrial cancer tends to be higher than those who have a hysterectomy for benign disease because of its association with obesity, as discussed in Chapter 2. In benign disease, Garry et al. (2004) reported an average BMI of 26 (overweight) but in a study with endometrial cancer patients Tozzi et al. (2005b) reported an average BMI of 31 (Class I obesity). These two studies reported within a year and differences can more readily be attributed to the indication for surgery, rather than general increases in obesity over time.

### 3.5.3.3 Incision

The type of incision is also relevant when comparing studies in benign disease, where the incision most commonly used is transverse. Garry et al. (2004) in the EVALUATE study of 1380 women having vaginal, abdominal or laparoscopic hysterectomy, reported that 88.7% of those having abdominal hysterectomy had a transverse incision but in the ASTEC study this was only 56% (ASTEC Study Group 2009).

### 3.5.4 Complication Rates

Possibly as a reflection of these differences, the comparisons with open surgery vary in the literature on benign disease. A higher complication rate has been identified in the laparoscopic cohorts (Garry et al. 2004; Meikle et al. 1997) and Nlieboer et al. (2009) concluded that laparoscopic hysterectomy had some advantages over abdominal hysterectomy, with less blood loss, rapid recovery,
fewer wound infections, but these were offset by the disadvantage of urinary tract injuries. However, Vaisbudh et al. (2006), in a retrospective analysis of laparoscopic and abdominal hysterectomy data of 167 women, found no differences in the complication rates between the two procedures.

In endometrial cancer the reported complication rates also vary. Fram (2002) demonstrated minimal intraoperative and postoperative complications for women undergoing both laparoscopic and abdominal hysterectomy but concluded that there was less blood loss, less need for analgesia and a reduced hospital stay in the laparoscopic cohort of this randomised study of 61 women. Zullo et al. (2005) studied 84 women randomly allocated laparoscopic or open hysterectomy and failed to demonstrate a significant difference in intraoperative complications but found lower postoperative complications in the laparoscopic cohort. Lower intraoperative and postoperative complication rates were seen in the laparoscopic cohorts of other studies (Tozzi et al. 2005b; Zapico et al. 2005; Occelli et al. 2003; Kim et al. 2005). Malzoni et al. 2009 also described lower complication rates in the laparoscopic group, concentrating on the complications of intraoperative damage, blood loss and postoperative fever, despite this being a prospective trial with the opportunity to examine a range of complications in more detail.

Magrina et al. (1999) demonstrated a intraoperative complication (for example, bladder puncture, ureteral damage, vessel damage) rate of 7.1% and a postoperative major complication (for example, deep vein thrombosis, myocardial infarction, port site hernia) rate of 16.1% with laparoscopic hysterectomy. The GOG LAP2 study identified a lower incidence of serious complications in the laparoscopic group over the open surgery group, 14% versus 21% (Walker et al. 2009). However, Malur et al. (2001) described significantly lower rates of blood loss and blood
transfusions but failed to demonstrate a statistically significant difference in postoperative complication rates when comparing open with laparoscopic hysterectomy and Litta et al. (2003) observed no difference in the rate of intraoperative or postoperative complications.

Mahdavi et al. (2006) compared laparoscopic hysterectomy performed for cancer with laparoscopic hysterectomy performed for benign disease and found no difference in intraoperative complications despite the older age range and longer operating time in the cancer cohort.

3.5.5 High Risk Surgical Groups

Initially laparoscopic surgery was reserved for fitter, younger and thinner women because it was believed that high-risk surgical groups should be given standard surgery and that age and obesity were relative contraindications (Childers et al. 1993; Reich & Roberts 2003). However, as this technology has developed, it appears that these are the groups of women who stand to benefit most (Elsenhauer et al. 2007; Eitabbakh et al. 2000; Holub 2003; Holub et al. 2000; Langebregke et al. 2002; Manolitsas & McCartney 2002; O’Gorman et al. 2009; O’Hanlan et al. 2004; Scribner et al. 2001; Tozzi et al. 2005b; Willis et al. 2006). This includes extremes, for example, Báilesta López et al. (2003) demonstrated the safety and reduced complications associated with laparoscopic surgery in 230 patients over the age of 70 years and Yu et al. (2005) and Pavelka et al. (2004) considered the morbidly obese with a BMI of >40. These represent the groups of women who are at the greatest risk of developing endometrial cancer (as discussed in Chapter 2) and those who are most likely to develop intraoperative and postoperative complications because of co-morbidities.
Despite this mixed picture of complications and complication rates associated with laparoscopic surgery and open surgery, it appears that there are no significant complication risks to prevent the use of laparoscopic surgery for endometrial cancer. The data suggests that endometrial cancer patients may be the group who stand to benefit more from a surgical risk perspective, when undergoing this procedure.

3.6 Cost

The financial implications of laparoscopic hysterectomy were considered in some reports but few studies carried out a cost analysis and some of the economic evaluations were flawed. The key features associated with cost appear to be operating time, surgical skill, use of disposable equipment, medication use and length of hospital stay.

3.6.1 Operating Time

Laparoscopic hysterectomy is primarily reported as taking longer to perform than open surgery in both benign and malignant disease (Dorsey et al. 1996; Fram 2002; Garry et al. 2004; Gemignani et al. 1999; Gli-Moreno et al. 2006; Litta et al. 2003; Lumsden et al. 2000; Mažoni et al. 2009; Melkile et al. 1997; Raju & Auld 1994a; Scribner et al. 1999; Sculpher et al. 2004 online; Valsbuch et al. 2006; Walker et al. 2009; Zapico et al. 2005; Zullo et al. 2005). However, there are some reports of LAVH having a shorter operating time than both TLH and open surgery as reviewed by Nieboer et al. (2009). Malur et al. (2001) and Kim et al. (2005) found no statistical difference in the operating times of LAVH and open surgery.

Increasing the length of a procedure has cost implications linked to theatre running costs and the volume of procedures that can be performed during the operating day. However, there is also evidence that the surgeon becomes faster and more efficient at laparoscopic surgery with experience, this is known as 'the learning
curve' (Childers et al. 1993; Holub et al. 2003; O’Hanlan et al. 2004; Valsbuch et al. 2006) or the ‘volume-outcome relationship’ (Watcher 2008). Surgical experience can also affect the amount of tissue dissected, the number of lymph nodes harvested and the complication rates (Holub et al. 2003). Valsbuch et al. (2006) suggested that the procedure can be performed with low complication rates even during the learning curve but that with experience the operation time, complication rates and hospital stays are decreased. Decreasing operating times were seen by Harkki-Siren and Sjoberg (1995), over the first one hundred procedures and Spirtos et al. (1996), over the first year. However, Magrina et al. (1999) maintained that laparoscopic hysterectomy with lymph node dissection remained a longer operation despite experience.

The experience level of the surgeon and/or surgical team is not always reported in the literature and Querleu et al. (1998) argue that studies comparing laparoscopic to open surgery which fail to report on what stage of the learning curve the surgeons are at, are unsatisfactory and not representative of the technique. As laparoscopic surgery becomes commonplace and part of junior doctor training it is possible that the reported operating time will decrease.

3.6.2 Disposable Equipment

Laparoscopic hysterectomy generally uses more disposable equipment during the procedure than open surgery (Dorsey et al. 1996; Gemignani et al. 1999; Lumsden et al. 2000; Sculpher et al. 2004 online). Where this figure is calculated the difference can be significant, for example, Gemignani et al. (1999) reported an operating room supplies cost of $1612 for laparoscopic surgery compared with $84 for the open procedure but Scribner et al., also in 1999, reported a more comparable cost of operating room equipment as $1202 in the laparoscopic group and $1097 in
the open surgery group. Neither study provided a breakdown of what was included in the costs and the differences in the cost of open surgery between the studies is more striking. Lumsden et al. (2000), in benign disease, removed the cost of disposables in theatre from their analysis without explaining the rationale for this and Spritos et al. (1996) refer to a more general 'operating room costs' but found no significant difference between the two procedures. Eltabbakh et al. (2000) reported a statistically significant difference in operating room charge but this is not defined and could possibly include the increased surgical team time. It has also been anticipated that when departments become more established in the use of laparoscopic surgery they will invest in reusable equipment which would reduce the cost of disposables (Reich & Roberts 2003).

3.6.3 Use of Medication

Medication use has been discussed in the literature in terms of anaesthesia, pain relief and also medications associated with complications, such as antibiotics for wound infections. Lower pharmacy but higher anaesthesia costs were seen in the laparoscopic surgery groups by Scribner et al. (1999) and Spritos et al. (1998). Eltabbakh et al. (2000) and Zullo et al. (2005) commented on the lower use of analgesia in the laparoscopic group but Raju and Auld (1994b) demonstrated no statistical difference in the use of analgesia. Lumsden et al. (2000), in benign disease, concluded that there was no difference in analgesic requirement but reported a higher use of antibiotics for women having open surgery. Sculpher et al. (2004 online) did not report on medication or anaesthesia use in their cost analysis study, while Fram (2002) mentioned a reduction in analgesia use in the summary but this was not qualified in the results.
3.6.4 Length of Hospital Stay

There seems to be little dispute in the literature about the reduction in hospital stay associated with laparoscopic surgery when compared to open surgery for both benign and malignant disease (Fram 2002; Gemignani et al. 1999; Garry et al. 2004; Gil-Moreno et al. 2006; Lumsden et al. 2000; Mazzoni et al. 2009; Meikle et al. 1997; Malur et al. 2001; Raju & Auld 1994a; Valsbuch et al. 2006; Zapico et al. 2005). In endometrial cancer, although the laparoscopic stay is shorter than the open surgery stay, there is considerable difference in the reported length of overall stays between studies. For example, 10 days versus 15 days (Kim et al. 2005), 8.6 days versus 11.7 days (Malur et al. 2001), 2.3 days versus 6.5 days (Fram 2002) and O’Hanlan et al. (2004) reported an average stay of 1.8 days for women having laparoscopic surgery. Length of hospital stay has been shown to be associated with hospital custom and practice and may not always be a reliable measure of fitness for discharge (de Jong et al. 2006 online). There appears to be no significant difference between women of an older age or higher BMI.

3.6.5 Specialist Surgery

Gynaecological oncology is a recognised sub-specialty of gynaecology and doctors in the UK train according to Royal College of Obstetricians and Gynaecologists (RCOG) standards (Royal College of Obstetricians and Gynaecologists (RCOG) 2008). Initially, laparoscopic surgery for endometrial cancer was carried out in cancer centres by accredited gynaecological oncology surgeons because of its experimental nature but according to government guidelines, women with early endometrial cancer can be surgically managed in diagnostic units (National Cancer Action Team 2008). Some authors warn that laparoscopic surgery for endometrial cancer requires skilled surgeons with adequate oncology training (Litta et al. 2003; Vinatier et al. 1996) and D’Argent (1993:294) warned of the
The dangers of laparoscopic cancer surgery should it became commonplace and 'fall into inexperienced hands'. The cost implications of this surgery resulting from altered referral patterns, has not been assessed.

3.6.6 Measuring Cost

Cost effectiveness was generally related to the reduction in hospital stay and reduced medication needs but few papers offered any formal analysis or reliable cost measurements. Of the studies that did report cost analysis, the results were mixed. Lumsden et al. (2000) concluded that laparoscopic surgery was significantly more expensive in their cost-utility analysis of 200 women randomised to LAVH or open hysterectomy in benign disease and Dorsey et al. (1996) suggested the increased cost was associated with the increased use of disposables and longer operating times, despite shorter hospital stays. The EVALUATE study in benign disease was analysed for cost by Sculpher et al. (2004 online). They reported little difference between laparoscopic hysterectomy and abdominal hysterectomy, considering cost effectiveness to be ‘finely balanced’ when taking into account theatre time and equipment, hospital stays, follow-up costs and health outcomes using Quality Adjusted Life Years (QALY’s). However, Raju and Auld (1994b) estimate an overall potential cost saving for LAVH when compared with open surgery. In the Cochrane Collaborative review, Nieboer et al. (2009) found no significant difference in the overall cost of laparoscopic hysterectomy and abdominal hysterectomy but did comment that few studies examine comparative costs.

In endometrial cancer, Gemignani et al. (1999) concluded that shorter hospital stays with laparoscopic surgery made it more cost effective overall. However, women in the open surgery group were significantly heavier which could affect length of stay but the analysis makes no comment on this. Spiritos et al.
(1996:1795) demonstrated cost savings for obese women but were more reserved in their overall conclusion stating that the ‘laparoscopic management of endometrial cancer may result in significant cost savings’. However, Scribner et al. (1999) concluded that the cost savings of shorter hospital stays were offset by the longer operating time. Despite the lack of cost analysis research the GOG LAP2 study did include a cost analysis (Walker et al. 2009).

3.7 Quality of Life

Cancer treatments aim to cure, lengthen survival and/or improve quality of life. Quality of life is subjective, multidimensional and covers all aspects of the health experience (Penson et al. 2006). Most of the papers reviewed alluded to improved quality of life based upon early mobility, low complication rates, short hospital stays and a rapid return to work. However, very few studies included quality of life as a main end point or used a quality of life measurement tool.

3.7.1 Measuring Quality of Life

Where quality of life was assessed using recognised measurements, it was primarily in the benign setting with two studies reporting in endometrial cancer. For a summary of the tools used and the results see Table 3.1.
Table 3.1: Table of studies measuring Quality of Life using a recognised tool to assess women having laparoscopic hysterectomy.

<table>
<thead>
<tr>
<th>Authors</th>
<th>Quality of Life Scale</th>
<th>Setting</th>
<th>Participants and Schedule</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ellström et al. (2003)</td>
<td>Psychological General well-being (PGWB), McCoy Sex Scale</td>
<td>Benign</td>
<td>74 women-baseline and 1 year post operation.</td>
<td>No significant difference between open and laparoscopic surgery.</td>
</tr>
<tr>
<td>Garry et al. (2004)</td>
<td>Short Form Health Survey (SF-12), EuroQol (EQ-5D), Visual Analogue Scale for pain, Sexual Adjustment Questionnaire</td>
<td>Benign</td>
<td>1380 women- 6 and 12 months post operation.</td>
<td>Laparoscopic hysterectomy shows some advantage at 6 months but no difference in the laparoscopic groups at 12 months.</td>
</tr>
<tr>
<td>Kluivers et al. (2007)</td>
<td>Dutch version of the RAND-36</td>
<td>Benign</td>
<td>59 women-followed to 12 weeks post operation.</td>
<td>Laparoscopic surgery scored favourably over open surgery on all aspects but only statistically significant in vitality.</td>
</tr>
<tr>
<td>Komblieth et al. (2009)</td>
<td>Function Assessment of Cancer Therapy-General (FACT-G)</td>
<td>Endometrial cancer</td>
<td>2600 women- 6 and 12 weeks post operation</td>
<td>Improvement in laparoscopic group at six weeks but not sustained at 12 weeks.</td>
</tr>
<tr>
<td>Lumsden et al. (2000)</td>
<td>EuroQol (EQ-5D).</td>
<td>Benign</td>
<td>200 women-4 weeks post operation</td>
<td>No significant difference between open and laparoscopic surgery</td>
</tr>
<tr>
<td>Persson et al. (2006)</td>
<td>Psychological General Well-Being (PGWB), Women’s Health Questionnaire (WHQ), Spielberger Trait Anxiety Inventory (STAI), Beck's Depression Inventory (BDI).</td>
<td>Benign</td>
<td>120 women- 5 weeks and 6 months post operation</td>
<td>No significant difference between open and laparoscopic surgery.</td>
</tr>
<tr>
<td>Zullo et al. (2005)</td>
<td>Short Form Health Survey (SF-36).</td>
<td>Endometrial cancer</td>
<td>84 women (plus 40 matched controls)- baseline, 1, 3 and 6 months post operation</td>
<td>Higher scores in the laparoscopic group throughout the study.</td>
</tr>
</tbody>
</table>

3.7.2 Pain, Length of Stay and Activity

Specific markers of quality of life were referred to throughout the literature. Spirtos et al. (1996:1795), in their cost and quality of life analyses, suggested that an improvement in quality of life in the laparoscopic management of endometrial
cancer was 'demonstrated by shortened hospital stays and an earlier return to normal activity'. Eltabbakh et al. (2000) used recall of pain, resumption of full activity, return to work and satisfaction with clinical management as their indicators. They demonstrated an earlier return to normal activity and work in the laparoscopic group but this did not reach statistical significance and there was no difference in pain recall or satisfaction.

Considering pain in both benign and malignant disease, Lumsden et al. (2000) found no significant difference in analgesia use, Garry et al. (2004) showed reduced pain in the laparoscopic group and Zullo et al. (2005) found no difference in immediate postoperative pain but a significantly different pain score on discharge from hospital and lower use of analgesia in the laparoscopic group.

Quality of life is subjective and measures such as, 'being able to return to work', may not always equate to improved quality of life for the individual. Spiritos et al. (1996:1799) found women in California described a rapid return to normal activity but did not return to work because they had six weeks of leave "coming to them". However, returning to work was more important to 100 Australian women where paid sick leave was limited to 10 days (Rosen et al. 1997).

3.8 Gaps in the Literature

Laparoscopic surgery involves three main stakeholders, patients, health professionals, and service providers. This can be seen as a triangle similar to the triangle of forces described in the Policy Review (Chapter 12). In situations of power this triangle may not be equilateral or stagnant; changing to denote the power that a stakeholder has at any given time (Salter 2004). The knowledge created from research can be used to highlight the needs of one group over another and the
literature reviewed with regard to laparoscopic surgery was primarily found in medical journals and no nursing research was identified.

Websites advertising the benefits of laparoscopic surgery to the public were identified, especially services in the US. With a large number of hysterectomies performed per year, 100,000 in the US and 550,000 in the UK (Sculpher et al. 2004 online), there is potentially a large market for this technology. In website advertising there is little differentiation between cancer and non-cancer surgery. The information available for the public describes the cosmetic advantages of laparoscopic hysterectomy, which is not discussed in the cancer medical literature, where wound incisions are generally referred to with regard to mobility, infection, hernia and pain (Kim et al. 2005; Kornblith et al. 2009; Malzoni et al. 2009; Walker et al. 2009; Yu et al. 2005). The only exception was a study of members of the Society of Gynecologic Oncologists (SGO) where 46% of surgeons who performed laparoscopic procedures, cited improved cosmesis as one of the reasons for doing so (Frumovitz et al. 2004).

Laparoscopic surgery in endometrial cancer from the patient perspective has not been explored, in benign or malignant disease. Some of the papers identified comment on patient preference, such as, Berker and Dokmeci (2002:389) who report that ‘the patient views (the) endoscopic surgery positively’ but this appears to be an assumption on behalf of the authors, it is not part of the study or appropriately referenced. Schlaerth and Abu-Rustrum (2006) ‘intuitively’ consider patient satisfaction to have driven the increase in minimally invasive surgery and Holub et al. (2002) studied women who were already booked to have laparoscopic hysterectomy determined by patient or doctor preference. Malur et al. (2001)
reported that 63 women out of 145 refused to be randomised, preferring instead to choose laparoscopic hysterectomy.

In a conference abstract, Kluivers and Opmeer (2007) presented the findings of a study of 49 patients who were interviewed and 39 nurses who completed a questionnaire regarding preference for laparoscopic and abdominal hysterectomy. Eighty-four per cent (84%) of the patients and 74% of the nurses expressed a preference for laparoscopic surgery based on the avoidance of complications and only 15% of the sample felt that twice the complication risk in laparoscopic surgery was unacceptable. All participants in this study underestimated the complication rates for hysterectomy in general. In a study of patients, managers and clinicians, a preference for laparoscopic surgery was demonstrated over open surgery in all groups, even when participants were quoted increased operating time, a higher major complication rate, and longer hospital stays (Hart et al. 2001). The reasons for these preferences, even when faced with disadvantages, are poorly understood.

Women are currently undergoing laparoscopic surgery for endometrial cancer; about 6% of women in the ASTEC study had their surgery recorded as being performed laparoscopically (ASTEC Study Group 2009). Ten percent of members of the SOG in the US performed laparoscopic surgery for uterine cancer in 2002 (Frumovitz et al. 2004) and this had increased to 43% by 2007 (Mabrouk et al. 2009). However, 93% of women in the ASTEC study did not have a laparoscopic hysterectomy and 57% of SOG members did not perform laparoscopic hysterectomy for uterine cancer in 2007. For patients, the choice to have laparoscopic surgery depends largely upon the surgeon's experience and preference (Davies & Magos 2001; Domingo & Pellicer 2009; Kolkman et al. 2007; McCracken et al. 2006). This procedure is not currently carried out in all gynaecological cancer units or centres.
and within centres, not all gynaecological cancer surgeons are performing the procedure, as demonstrated in the audit of practice in the Service Development Project presented in Chapter 13.

Women who are offered laparoscopic surgery have surgically based information on which to understand their potential treatment. All the literature can offer at this time is an assurance that laparoscopic hysterectomy is at least as good as open surgery and results in a shorter hospital stay compared to women in the same unit/centre that have open surgery. It was anticipated that the GOG LAP2 study would answer the remaining questions with regard to laparoscopic hysterectomy for endometrial cancer (Gil-Moreno et al. 2006; Malzoni et al. 2009; Schlaerth et al. 2006), allowing the debate to move on to robotic surgery (Mabrouk et al. 2009; Seamon et al. 2009). However, the GOG LAP2 study did not attempt to assess anything more than adequacy of specimen, operative time, morbidity, length of stay, patterns of recurrence, disease-free survival, survival and quality of life using the FACT-G questionnaire (Kornblith et al. 2009).

An understanding of this technique from the perspective of women who have undergone the procedure remains unstudied. This gap in the literature results in keeping the focus of this technology in the domain of the professionals and providers which is likely to lead to an uneven balance of power. It was this gap that the study aimed to address.

3.9 Summary of Chapter

The medical literature to date has generally found the use of laparoscopic surgery to be safe in the management of endometrial cancer but long-term survival data remains limited. Complication rates are low and quality of life is not adversely affected. There is some evidence to suggest that the procedure is associated with
less pain in the postoperative period and shorter stays in hospital are seen in comparison to women having open surgery in the same department.

Data on cost is difficult to interpret, with suggestions that in relation to open surgery, the laparoscopic route is more expensive, about the same or has the potential for cost savings. The main cost issues centre on increased operating time, use of disposable equipment in theatre and medication use but an earlier discharge from hospital is associated with laparoscopic surgery. This type of surgery is being carried out by some gynaecologists but it is not being offered to all women with endometrial cancer.

There is limited understanding of the wider aspects of this technology and how it is understood by the individuals who experience its use. There is no research from the perspective women who have undergone the procedure and this has potentially led to an unbalanced view of this technology. This gap in the literature forms the basis of this study.
CHAPTER 4: METHODOLOGY

4.1 Introduction

This chapter presents the reasons for using Heideggerian hermeneutic phenomenology in this study and why this methodology was best suited to developing an understanding of the experience of laparoscopic surgery for endometrial cancer. The philosophical underpinnings of the main research paradigms are discussed together with the personal perspective of the author. This chapter goes on to describe the origins of phenomenology and how it is used as a research methodology.

4.2 Research Paradigm

A scientific paradigm is defined as ‘a conceptual or methodological model underlying the theories and practices of a science or discipline at a particular time’ (Oxford English Dictionary (OED) 2009 online) and was first described by the philosopher and historian of science Thomas Khun (Chalmers 1999). Currently, there are two main approaches to research which would be considered as the two main research paradigms. They are often described as quantitative and qualitative, however, these are actually adjectives which describe data collection and analysis (Royal College of Nursing 2004) and more recently the terms positivist and interpretive have been used (Mackey 2005).

4.2.1 Positivism

Positivism is a philosophy closely associated with modernism (Thomas & Brubaker 2008). It emerged from the period of Western philosophy known as The Enlightenment which saw a shift in thought from the doctrine or teachings of the church to knowledge based upon reason and natural law (Stevenson 2002).
Positivism is generally concerned with the observable and measurable (quantitative) and in research it has been primarily associated with detached observation and controlled experiments of the empirical-analytic paradigm (Haase & Myers 1988).

Positivist assertions are based on a belief in an objective real world beyond the body of the individual which can be known, described and verified (Thomas & Brubaker 2008). Positivism is the principal paradigm on which modern science has been based, it places a high value on the removal of other influences or variables in the research setting and is concerned with information gained by observation, experience and experiment (empirical) which is analysed (hence empirical-analytic paradigm) using mathematical models, and the testing of theory or hypotheses (Hasse & Myers 1988; Koch 1996; Krauss 2005; Mackey 2005; van Manen 1990).

Dissatisfaction with the limitations of positivism to describe people's lives led to a revision of ideas and the development of postpositivist and postmodern thought. However, positivism remains the dominant paradigm in medical research where the randomised controlled trial is considered 'the gold standard', as discussed in Chapter 3.

4.2.2 Interpretivism

The interpretive research paradigm aims for understanding rather than explanation, description and prediction; advocating that research be carried out on conscious beings in a natural uncontrolled setting (Mackey 2005). Interpretivism is based upon a relativistic philosophy which asserts that there is no objective reality but multiple realities constructed by human beings (Krauss 2005). Therefore, we can not understand the object world independent from our perceptions of it. Interpretive studies assume people create subjective meaning through interaction with the world.
around them and attempt to understand phenomena by accessing the meanings that individuals assign to them (Krauss 2005). Interpretive research primarily uses qualitative or non-numerical data collection methods originating in the traditions of philosophy, anthropology and sociology (Koch 1996).

4.2.3 The Art and Science of Nursing

Wilson (2002) considers the methodological position of the researcher as representing his or her view of reality: the positivist sees facts of the world represented in real objects and the interpretivist sees the world in terms of subjectively constructed meanings. This suggests a static quality, a fundamental belief that places researchers, as individuals, in one paradigm or another. However, as a student nurse in the early 1980s, I was aware of a dichotomy of values and beliefs evident in nursing theory and practice.

In preparation for a career in nursing, I studied biology and gained grounding in the empirical-analytic model and its application in the biological sciences but I also studied English and appreciated the overwhelming need for human beings to define meaning in the narrative of their individual lives or stories. Krauss (2005) describes this need as one of the most fundamental aspects of human existence. Being taught about medicines, which is based on prediction and mass effect, alongside ethics and complex dynamic concepts like caring and prejudice (HIV was the main health issue occupying the media at the time) introduced the potentially opposing principles in nursing and how they co-exist in nursing practice. This combining of traditional positivist science with a desire to understand the unique perspective of patients in the context of their illness, lives and interaction with the world, has been called the art and science of nursing and, although nurses often associate the positivist
paradigm with medicine (Bond 1993), the same debate also exists in medicine (Morrell 2000 online) and psychology (Kvale 1992).

The Enlightenment, with its modernist and positivist ideas represented a rejection of previous thought, primarily metaphysics, but postpositivism is not considered to be a rejection of positivism. Steiner Kvale (1992) in his introduction to *Psychology and Postmodernism* considers a postmodernist approach to be a recycling and collage of elements of tradition in new contexts rather than erasing and starting anew. Interpretivism can be seen as building upon positivism to develop a more complete sense of the world through a different type of knowledge. Weber (2004 online) suggests that positivist and interpretivist research are not so dissimilar as to be considered opposing and goes on to argue that different types of research methods and data analysis have different strengths and weaknesses that result in different types of knowledge. Reflecting on this, I considered myself to have been inherently comfortable with the co-existence of these paradigms when choosing an art and a science in preparation for a career in healthcare and I have maintained that position throughout my career.

Haase and Myers (1988) proposed that deciding on a research paradigm can be based upon individual values and beliefs but can also depend upon the purpose or subject under investigation. Krauss (2005) agrees that choosing a methodology depends upon what is being asked and not a commitment to a particular paradigm and health researchers are increasingly using interpretive research designs to illuminate the contextual dimensions of health, wellness and engagement (Wilding & Whiteford 2005). Individuals cope with complex, changing systems of values and beliefs whether they are researchers or participants in a study. I see my own methodological position as one of pluralism, where these paradigms co-exist,
together with pragmatism, where truth is defined by what works rather than theories, similar to the methodological position identified by Bond (1993) in Nursing: Art and Science.

4.2.4 Interpretive Investigation

Laparoscopic surgery is a relatively new technique that has emerged from the application of technological developments in surgery. Surgeons saw an opportunity to use optical technology to view and operate inside the body and began with the question 'can it be done?' (Reich et al. 1989). The application of laparoscopic surgery has been shown, in Chapter 2, to involve three main stakeholders: healthcare professionals (primarily the surgeon), patients and providers or funding bodies. Having established that the uterus could be removed from the pelvic cavity using a laparoscope, the medical debate moved on to incorporate the themes identified in Chapter 3, namely safety and efficacy, complications, cost and quality of life. This research has primarily been from a positivist perspective using numerical data to test assumptions, even in issues relating to quality of life, for example, counting the number of analgesia administrations to assess level of pain (Eltabbakh et al. 2000; Zullo et al. 2006). The benefits for patients have been deduced and then tested (deductive reasoning); as a consequence all that can be said about the procedure is how safe and effective it is, the type and level of complications as seen by surgeons, the relative cost and the effect of the procedure on predefined daily functioning.

For healthcare professional working with women with endometrial cancer, it is important to be able to give reassurance about the safety of laparoscopic hysterectomy and its likely consequences but what is missing is a way to describe the surgery with a level of understanding of 'what it is like'. Part of the specialist
nursing role in cancer is to translate medical knowledge into a language that fits the context of the patient's life. In an analogy to an experience like giving birth or becoming a parent, a description could include what it is, what happens and the likely consequences but 'what is it like?' is a question that can only be answered if those that have had the experience share its meaning with others.

To develop an understanding of the experience of laparoscopic hysterectomy, an interpretivist approach would be concerned with the perspective of the women undergoing the procedure and what it means to these women to have this type of surgery. As Wilding and Whiteford (2005) point out, this type of research approach allows the participant, as the one with the experience, to be in the position of expert and the researcher in the position of learner. This is in keeping with the concept that undergoing the procedure is subjective and individual to each woman but interpretive research can be used to gain an inductive understanding of the phenomenon (inductive reasoning) on which to develop a theory or hypothesis for testing using a positivist approach, if appropriate.

Within the interpretive paradigm there are numerous overlapping research approaches such as grounded theory, ethnography and phenomenology. Phenomenology is a philosophy applied to the study of phenomena and human experience which evolved from questions of ontology, the nature of being, and epistemology, the nature of knowledge and is one of the methodologies which is considered by many to sit within the interpretive research paradigm (Cohen 2000; Haase & Myers 1988; Hamill 1994; Racher & Robinson 2003; van Manen 1990). Phenomenology brings language perception to phenomena of human experience (Carpenter 2007a) and is arguably more suited to the aim of describing the phenomenon, laparoscopic surgery for endometrial cancer, from the perspective of
the women undergoing surgery, as opposed to developing 'a theory about dominant social processes' (Carpenter 2007b:133) as seen with grounded theory, or from a cultural perspective as seen in ethnography (Streubert Speziale 2007b).

4.3 Phenomenology

The concepts of phenomenology originate with the philosopher Franz Brentano who said that whenever we think, we are thinking about something and this he termed intentionality (Dowling 2007). According to this theory ideas are not simply objective but have significance and meaning depending upon how we feel about them (Stevenson 2002).

Phenomenology was developed into a philosophy by Brentano's student Edmund Husserl, a German mathematician and philosopher, whose dissatisfaction with the objectivism of modern science led him to search for a rigorous scientific method without preconceptions or hypothesis, as a way to more adequately interpret the world in which we live (Holm & Liianson 2007 online). Husserl took the concept of intentionality and developed it into the philosophy of phenomenology, which seeks to understand the relationship between the world and the senses that experience it, the world as we experience it as conscious beings (van Manen 1990). Phenomenology is based in a paradigm of personal knowledge and subjectivity. It emphasises the importance of personal perspective and is a tool for understanding subjective experience, gaining insights into people's motivations and actions, removing taken-for-granted assumptions and traditions (Toombs 2001). Pure phenomenological research seeks to describe rather than explain and starts from a perspective free from hypotheses or preconceptions (Husserl 1970). There are a number of schools of phenomenology which have many commonalities but also distinct features which differ (Dowling 2007).
Martin Heidegger, a student of Husserl, developed his own concept of phenomenology by shifting from consciousness to being. This he called *Dasein*, which was explained by Dreyfus (1991) as a literal translation from German to mean everyday human experience but he equated it with the English term 'human being', as a way we characterise all people or a specific person. Heidegger (1962) saw humans embodying how to be, rather than thinking how to be. Understanding the lived experience marks the philosophy of Husserl and Heidegger as a method of research.

Philosophical ideals are considered critical to research; they provide continuity and coherence to the conduct of the study and the outcome (Mackey 2005). Phenomenology has become increasingly used as a research methodology in nursing (Cohen 1987; Crotty 1996; Lawler 1998; Mackey 2005). It is used to answer questions of meaning, to understand an experience as it is understood by those with experience of it (Cohen 2000). Phenomenological studies concentrate on human experiences which are examined through the detailed descriptions of the people being studied without considering questions of causality, objective reality or even outward appearances (Wilson 2002). As a methodology, it involves studying a small number of subjects in detail and has been used to develop patterns and relationships of meaning (Kralik et al. 1997; Lawler 1998; Mackey 2007). When choosing between the two main philosophical schools of Husserl and Heidegger for this study, two main differences were considered; phenomenological reduction and interpretation or hermeneutics.

### 4.3.1 Phenomenological Reduction

Husserl believed the researcher should remove preconceptions, prejudice and prior experience from the research setting (some argue that by attempting to remove
bias places Husserl's method in the positivist paradigm) (Dowling 2007; Paley 1997). Husserl referred to this as phenomenological reduction or epoché which has become associated with the metaphor 'bracketing' (Paley 1997). The focus of Husserl's phenomenology is epistemological, to reveal knowledge which can transcend human experience (Mackey 2005). Heidegger's philosophical concerns are ontological; an understanding of being itself (Heidegger 1962).

Heidegger believed that it is not possible to 'bracket' and that human beings cannot be separated from their perceptions even in the research setting (Heidegger 1962), thus defining our understanding as a part of us that cannot be removed from our thinking (Smythe et al. 2008). Humanist and feminist researchers also dispute starting without preconceptions or bias, and emphasise the importance of making clear how interpretations and meanings have been placed on findings and exploring the role of the researcher as an interested and subjective participant rather than an impartial observer or manipulator (Lowes & Prowes 2001; Plummer 1983; Sass 1989). It is this fundamental difference in perspective about the ability to 'bracket' that is often used by nurse researchers as justification for applying Heideggerian philosophy to nursing research (Crotty 1996; Dowling 2007; Mackey 2005; Paley 1997).

Interpretive research uses the researchers as instrument, to interpret or measure the phenomena that they are observing (Bond 1983; Weber 2004 online). As a specialist nurse in the field of gynaecological cancer, I entered the research setting with conscious and subconscious ideas, knowledge and experience. Although Crotty (1996) and Paley (1997) argue that Husserlian bracketing has been misinterpreted by nurse researchers to represent an exploration of bias rather than a suspension of belief in the outer world, it seemed appropriate to accept my
experiences and perceptions, consciously considering them in the interpretation of the data, in keeping with Heideggerian methodology. Weber (2004 online) considers an understanding of bias to be at the heart of all research: in positivism attempts are made to remove it and in interpretivism attempts are made to recognise and describe it. There may also be an interaction between the researcher and participant that relies upon gender, especially in a conversation between two women about a gynaecological procedure and also on a shared experience of laparoscopic surgery as a patient who has been nursed through the procedure and a nurse who has nursed others through the procedure. Heideggerian phenomenology allows for the awareness of one’s own consciousness, as a coping being, already involved in the world (Dreyfus 1991). Allowing the researcher to be in-amongst-it-all and not just an observer (Dreyfus & Wrathall 2006) fits with my understanding of the philosophical underpinnings of phenomenology as it can be applied to research in the context of nursing, human interaction and interpretation.

4.4 Hermeneutics

Hermeneutics is a branch of philosophy concerned with interpretation and understanding (Ramberg & Gjesdal 2009 online). The word is derived from Hermes, the Greek god, who communicated messages from the gods to ordinary mortals and it has traditionally been concerned with the interpretation of biblical texts (Draper 1996; Hamill 1994; van Manen 1990). Hermeneutics is a specific system or method for interpretation, or a specific theory of interpretation (Gadamer 2004; van Manen 1990). In Heidegger’s move away from Husserl’s ‘bracketing’ he describes the need for interpretation and not description, as Williamson (2005:61 online) asserts, ‘facts speak for themselves but through the lens of interpretation’. Heidegger challenged Husserl’s construction of phenomenology as purely descriptive and considered the concept of description without interpretation to be impossible (Koch 1996; Mackey
2005). Heidegger (1962) advocated the use of hermeneutics as a research method founded on the view that the lived experience is an interpretive process, that life is like a text, and the purpose of our lives is to understand or interpret that text.

Hermeneutics allows the researcher to ‘respect and retain the perspective of the participant while simultaneously approaching the text from a different horizon of meaning’ (Draper 1996:50). In the description of Heideggerian phenomenology, the researcher has been established as a participant in the research and not a passive observer but it is also important for the researcher not to ‘read the text as the devil reads the Bible, attending only to those portions that support preconceived notions’ (Draper 1996:50). The process of hermeneutic interpretation allows for a dialogue between the voice of the participant as expressed in the text and the theoretically informed researcher (Draper 1996). To achieve understanding the researcher is required to go beyond the literal meaning of the text to pursue the fore-structure and thematic meanings (Mackey 2005). Each part of the text is considered in relation to the whole. This interpretation and pursuit of meaning hidden in text aims to provide richness to the understanding of laparoscopic surgery in endometrial cancer that I feel cannot be obtained with description alone. Heidegger’s philosophy is interpretive or hermeneutic and was the second reason for choosing Heideggerian phenomenology.

To pursue depth of meaning in the text, it was necessary to revisit the text many times; taking the meaning extracted and applying it back to the text. This iterative process of returning to the text is called the hermeneutic circle or cycle.

4.4.1 Hermeneutic Circle

Heidegger (1962) considered interpretation to be a circular process moving between the part and the whole as a reflective, ongoing process. The fore-structure
is prior awareness, what is already known or understood before interpretation. This circular process sees the fore-structures made explicit, considered in terms of the whole understanding, reconsidered in new ways, to become the new fore-structure and so the circle continues (Mackey 2005). Heidegger (1962:195) called this the 'circle of understanding' and as human beings we are considered to always be in a hermeneutic circle (Plager 1994). Conroy (2003 online) described the hermeneutic circle as more of a spiral where the closed loop of the circle has been loosened, the spiral representing the circle stretched out. It is with this reinterpretation of the text that Heideggerian hermeneutic phenomenology seeks to discover what is already there but is simply hidden from view. During this study supervision was the process by which the hermeneutic circle was formalised and supported.

4.5 Summary of Chapter

Phenomenology is a philosophy and research methodology based on understanding the world in relation to how we, as human beings, sense or interpret it. It has primarily been associated with the interpretivist research paradigm which aims to understand the multiple realities constructed by human beings, rather than explain, describe or predict an object reality. Nursing combines an understanding of the empirical-analytic paradigm with the unique perspective of individuals and how disease is experienced in the context of people's lives. A Heideggerian hermeneutic approach was identified as the most appropriate way to develop an understanding of laparoscopic surgery as interpreted by women who had lived the experience, recognising but not removing the knowledge and experiences of the nurse researcher from the research setting.
CHAPTER 5: METHOD

5.1 Introduction
This chapter describes and discusses the rationale for the research methods used within the framework of phenomenology, which include sampling, data collection and data analysis. This chapter also includes a discussion on the ethical considerations and concludes with the steps taken to ensure rigour and trustworthiness.

5.2 The use of interviews
A variety of methods for obtaining data can be used in interpretive and phenomenologically based research. These include interviews, conversations, participant observation, action research, focus groups and analysis of personal texts (Carter & Henderson 2005; Polit & Hungler 1997). The general principles concern minimum structure and maximum depth. In the human sciences, information can be effectively gathered by direct questioning (Polit & Hungler 1997), as the psychologist Steiner Kvale (2007:7) said ‘if you want to know how people understand their world and their lives, why not talk to them?’ and the use of interview is one way to do this.

Interviewing allows the researcher to interact with the participant and explore the answers, to gain deeper meaning or clarification if necessary (Oppenheim 1992). Standardised interviews can be used to obtain quantitative data, for example, opinion polls and market research; but exploratory interviews generate in-depth qualitative data (Oppenheim 1992). Moustakas (1994:84) recommended the use of in-depth interviews for phenomenological studies as a way of gaining ‘evidence derived from the first person reports of life experiences’.

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Interviews can develop a two-way conversation which can be led by the participant (Carter & Henderson 2005; Oppenheim 1992; van Manen 1990). The establishment of a good level of rapport and empathy is critical to obtaining depth of information, particularly when investigating issues where the participant has personal experience (Plummer 1983). In any conversation, it is easier to maintain flow and interest when there is genuine empathy and rapport. A face-to-face interview allows the researcher and participant to develop a relationship and gives the researcher the opportunity to react to non-verbal responses made by the participant, making use of all available senses to judge the level of understanding and avoid misinterpretation (Polit & Hungler 1997).

Exploratory interviews can be semi-structured or unstructured and ask a number of questions which are planned but flexible (Carter & Henderson 2005). In semi-structured interviews, the researcher is looking to pose a series of defined questions but unstructured interviews tend to be used when the researcher has no 'preconceived view of the content or flow of the information gathered' (Polit & Hungler 1997:201). Using unstructured interviews as a data collection method, is in keeping with the philosophical underpinnings of phenomenology, where the researcher is attempting to uncover what is hidden and gain insights into the meanings the participants give to their own experience (Royal College of Nursing 2004). Unstructured interviews are particularly valuable where there is no prior theory.

It was for these reasons that unstructured face-to-face interviews were used in this study.
5.3 Sample

The research population represents the group or entire set of subjects with the characteristic to be understood and for this study, would be all women having laparoscopic surgery for endometrial cancer. The sample of a population to be studied can be selected using probability or non-probability sampling techniques (Marshall 1996; Polit & Hungler 1997). Probability sampling is based on the concept of random allocation of people or events that will be representative of a cross-section of the whole population being studied, so that the results of the study sample can be generalised back to the whole population (Marshall 1996). Non-probability or naturalistic sampling is conducted without knowledge or concern about whether those included in the sample are representative of the overall population (van Manen 1990).

The defining characteristic of non-probability sampling is that the choice of people or events is not a random selection. In interpretive research, there is no benefit in randomly selecting individuals because representation and generalisability are not the purpose of the exercise (Benner 1994; Marshall 1996; Streubert Speziale 2007a; van Manen 1990). Phenomenology relies on the experience of the individual and the richness of the description they offer. The aim of participant selection in this methodology is to study those who have had the experience, are willing to talk about it and who are diverse enough to ensure richness and depth (Colaizzi 1978; Laverty 2003 online; van Manen 1990).

Non-probability sampling is broadly covered by convenience sampling, purposive or judgment sampling, quota sampling and theoretical sampling (Marshall 1996; Polit & Hungler 1997). Purposive samples are hand-picked by the researcher as typical, based upon the researcher's knowledge of the population and elements
of interest (Polit & Hungler 1997). Phenomenology is well suited to purposeful sampling, permitting the selection of interviewees whose qualities or experiences show an understanding of the phenomenon in question. This type of sampling was chosen to select women for this study because the aim was to explore the experience and the quality of the data, not the quantity, was expected to influence the findings. This is considered the strength of purposive sampling in phenomenology (Nachmias 1996).

There were other issues that needed to be considered about the sample required for this study, such as, sample size, timing of the interviews in relation to surgery, indication for surgery, need for adjuvant treatment and effective communication. These are described below.

5.3.1 Sample Size

The sample size, in studies using qualitative research methods, is unlikely to be known with precision or certainty at the beginning of the study and usually emerges as the study progresses (Carter & Henderson 2005; Marshall 1996). It is not subject to power calculations or analysis (Sandelowski 1995). This goes against the philosophical underpinning of positivist research approaches, which use mathematical models to ensure the sample can represent the population. Estimating the number of participants required to complete a qualitative research project depends on factors including the quality of the data from each participant, the scope of the study and the nature of the topic (Morse 2000). However, small numbers generally allow for a greater depth of investigation and Sandelowski (1995) suggests that sample sizes should not be too small to achieve data saturation nor too large to undertake a deep case orientated analysis.
Saturation and redundancy are terms used to describe the point at which the researcher hears or reads similar kinds of information from the data. In grounded theory, the concept of saturation is used to describe the point at which the categories or themes are identified and no new information is obtained from the participants. Although some of the language used in relation to saturation is associated with grounded theory, in phenomenology, saturation can be seen to be the point at which there is enough data to complete a phenomenological description (Cohen 2000). The point at which the study reaches data saturation or data redundancy is the point at which recruitment stops. In phenomenology, where studies aim to explore individual experience, Morse (2000) and Creswell (1994) suggest six to ten participants as a guide to when saturation is likely to be reached.

Morse (2000:3) also suggested that ‘it is wise to overestimate the sample size’ and given that, prior to the study, there was no way of knowing the depth of the data that would be obtained from each individual participant, ethical approval was sought for up to 25 participants. This was an overestimation based upon the number of women who had undergone laparoscopic surgery in the previous year. A total of 14 women were interviewed for this study. Data collection was stopped when patterns in the data were continuously emerging suggesting data saturation had been reached and the richness of data were sufficient to complete a phenomenological description.

5.3.2 Timing

When considering the study of life experiences, Mapp (2008) comments on the sample representing participants who are living the experience as well as those who have lived the experience in the past and Cohen (2000:3) refers to ‘an experience as it is understood by those who are having it’. However, van Manen (1990)
considers hermeneutic phenomenology to be retrospective not introspective, relying on the reflection, memory and interpretation of the participants and suggests that it is not possible to reflect on an experience while experiencing it. It was considered to be in keeping with the philosophy of hermeneutic interpretation to only recruit women who had undergone laparoscopic surgery, rather than those undergoing the procedure.

There was limited information about what could be considered the appropriate length of time past an experience a participant should be. One could postulate that life experiences remain with us and shape who we are, suggesting that the meaning of an experience can be uncovered at any point in time, as expressed by Smythe et al. (2008:1390): 'thinking arises from all that has come before in one's life'.

At an early presentation of the study, a gynaecologist asked if recall of the experience would change over time. He described having met women who immediately after childbirth would consider the experience very differently to those a year later: from 'never again' to 'trying for another'. In phenomenology the aim is to strip away the taken for granted and uncover what Heidegger described as the 'essence' (Wesen), that which endures or is present. Given this understanding, the experience of childbirth would remain the same and time would not alter the meaning for the individual but the experience may be altered as culture and society change. However, it might be more difficult to recall the experience as time goes on, making it more challenging to uncover the meaning and because of this, I decided to approach women who had undergone the procedure in the past year, which was an arbitrary figure. One participant was discovered to be over a year from surgery at interview but her interview data was rich and descriptive and, in hindsight, the cut off point of one year was unnecessary. For Tobin & Begley (2008), in a
phenomenological study of 10 patients receiving a cancer diagnosis, the ethics committee restricted participation to patients over five years from diagnosis.

5.3.3 Benign or Malignant Disease?

Laparoscopic hysterectomy is performed for both benign and malignant conditions. The medical research with regard to laparoscopy for malignant disease concentrates on the effectiveness of treatment in terms of cancer recurrence, as discussed in Chapter 3, which is appropriate when studying a new technique that may compromise survival. However, when considering the experience of women undergoing laparoscopic hysterectomy, it was important to consider whether the experience of the surgery for cancer was different from the experience of the surgery for non-cancer conditions.

There were three main points to consider. Firstly, cancer is a life threatening disease and any consideration of surgery occurs within this context. Having a hysterectomy for benign disease may result from severe symptoms which are affecting overall health or the symptoms may be relatively mild and nothing more than a nuisance (Domingo & Pellicer 2009). Women can be reluctant to have surgery for benign disease and resort to surgery only after other avenues have been explored or if symptoms worsen (Learman et al. 2007). Cancer patients, however, are often relieved to be able to have surgery because it is recognised that surgery offers the best hope of cure for most cancers (Department of Health (DH) 2007). Secondly, the issues regarding the cosmetic value of laparoscopic surgery in endometrial cancer have not been explored, possibly due to the serious nature of the disease and the perceived superficial nature of vanity and cosmetic effect. And thirdly, time to understand and accept disease differs for a cancer patient. A woman who has surgery for benign disease may have been suffering for many years and
make a considered choice to have surgery. Cancer treatments, however, should be performed within 62 days of a patient presenting to a General Practitioner and within 31 days from diagnosis, according to Government standards (Department of Health (DH) 2000a). A woman may have been given a cancer diagnosis one day and operated on the next. In this study most women were treated within two weeks or less of their diagnosis, as described in Chapter 7.

Although, there was very little qualitative research regarding women who have had laparoscopic hysterectomy for any indication, I considered the experience of women with cancer to be so fundamentally different from women who do not have cancer, as to make it potentially a different experience. According to NHS guidelines (National Cancer Action Team 2008) women with benign disease are also managed in a different way, which was out of my own clinical specialty and experience. For these reasons, I considered it appropriate to only consider women who had laparoscopic surgery for endometrial cancer.

There was, however, one participant who had undergone her surgery for endometrial cancer but on final histopathology review her disease was defined as complex atypical hyperplasia, which is a premalignant condition. The experience she had up until the final diagnosis was confirmed, was the experience of laparoscopic surgery for endometrial cancer and her data was included in the study.

5.3.4 High Risk Disease

Women who are found to have high risk disease on histopathology are currently advised to have adjuvant radiotherapy, as discussed in Chapter 2. The prognosis and side effect profile of treatment are significantly altered with the introduction of radiotherapy. This had the potential to complicate the study and make it more difficult for these women to focus on the surgery and not other parts of
the treatment pathway and prognosis. Women with high-risk disease were, therefore, excluded from the study. However, one participant had her pathology upgraded and was awaiting radiotherapy at the time of her interview. Using Coiaizzi's (1978) framework, issues not relating to the phenomenon were screened out from the analysis (Chapter 7) and so this concern did not distract from the phenomenon and data from this participant were also included in the study.

5.3.5 Use of English

Hermeneutic phenomenology relies on interpretation of the spoken word. Any secondary translation may alter the meaning and change the ability of the researcher to interpret what was said by the participant. Requiring participants to be able to communicate effectively in English (as the language of the researcher) is in keeping with Coiaizzi's (1978) framework for analysis of phenomenological research. English was not the first language of one of the participants but she could effectively communicate in English, however, she initially chose to have her daughter tell her story while she interjected but gradually the participant took over from her daughter as the interview progressed.

These were the inclusion criteria on which ethical approval was sought to be able to approach women for consideration of this study.

5.4 Ethical Considerations

Ethical considerations inform all types of research and the main principles involved in medical ethics are, beneficence, non-maleficence, respect for autonomy, confidentiality and justice (Royal College of Nursing 1998). These were the principles used to guide the ethical considerations of the study.
The aim of this study was to increase the depth and availability of research which can be used to improve services with regard to laparoscopic surgery in endometrial cancer and is in keeping with the ethical principle of beneficence.

Although it was not anticipated that the study would harm the participants, there was a possibility that exploring a reasonably traumatic experience may bring suppressed emotions to the surface and induce distress. As a specialist cancer nurse, I have experience in managing the potential distress of a cancer diagnosis and the consequences of treatment, however, the relevant Clinical Nurse Specialist and Associate Specialist agreed to be named contacts, available to see any of the participants who may have become unduly distressed by the interview, or who felt the need for more information or support. The participants also had access to specialist counselling services as part of psychological support offered at the cancer centres. The uncovering of suppressed emotional distress is a possibility at any point in a cancer journey and was not considered an unacceptable risk in this study.

Individuals who have been given a diagnosis of cancer are extremely vulnerable. They may feel obliged to participate in research to ensure that their healthcare is not compromised (Burns & Grove 2006). The women asked to participate in this study were informed both verbally and in writing of the voluntary nature of their contribution and that participation or non-participation would not affect clinical care (Appendix 2). As researcher, I was not involved in the clinical care of the participants in this study.

The participants were assured of anonymity and data, in this study, have been stored in accordance with Local Research Ethical Committee (LREC) requirements. As a Registered Nurse, I am bound by the Nursing and Midwifery Council Code of
Professional Conduct (2004) and have also worked cancer clinical trials, receiving formal training in Good Clinical Practice (GCP).

Ethical approval was sought and granted from the Local Research Ethical Committee (LREC) (Appendix 1). The ethics committee stipulated that participants were to be recruited at follow-up clinic and not by letter, as initially requested. The participants were given details of the study findings and formally thanked for their participation.

5.5 Recruitment

The initial intention had been to recruit participants from one cancer centre. The laparoscopic surgeon there had performed over 25 laparoscopic hysterectomies for endometrial cancer in the previous year. However, although a large number of women had undergone the procedure, the surgeon had underestimated the number of women with high-risk disease who would be ineligible. Ethical approval had been sought for up to 25 participants and although this was an overestimation, as discussed, it remained unclear how many women would agree to take part and how detailed the descriptions would be. Also, because the Ethics Committee had stipulated that participants be approached in the follow-up clinic, it was anticipated that recruitment would be slower, as eligible women only attended clinic every three months. These two unexpected events raised concerns that data saturation may not be achieved within the time constraints of this study. Therefore, a second laparoscopic surgeon at a neighbouring cancer was approached and ethical approval sought to open the study at a second site. This was granted.

Once recruitment commenced at the second site it became apparent that the second laparoscopic surgeon had also underestimated the number of women diagnosed with high-risk disease on final pathology, although, with two participating
cancer centres this did not affect overall recruitment. This underestimation by the surgeons possibly reflects the concentrated involvement of the surgeon in the surgical part of the endometrial cancer pathway and not the whole pathway.

Also, the percentage of women who had high-risk disease was around 50%, which was greater than the anticipated 19.2% (Lee et al. 2006), as discussed in Chapter 2. The higher rate of women with high-risk disease at these cancer centres may also demonstrate the practice of diagnostic or local units operating on women with early stage disease and not referring them to the cancer centre, as discussed in the Service Development Project presented in Chapter 13.

Details of women who had undergone laparoscopic surgery for endometrial cancer in the past year were accessed via the surgical and histopathology databases. Histopathology results for these women were reviewed for stage and grade of disease. As eligible women attended for clinic appointments, they were approached by the medical team and given details of the study (Appendix 2). All those approached agreed to be contacted by a researcher and all agreed to participate in the study.

Oppenheim (1992) recommends interviewing away from the hospital environment as it may be perceived as unpleasant or threatening and so the women were offered a choice of being interviewed at the treating hospital out-patients department, a neutral hospital or in their own home.

5.6 The Interview

Twelve women chose to be interviewed in their own home and two chose to be interviewed in the hospital setting. A compact tape recorder was used to record the interviews.
The interview was carried out by establishing an environment of trust and safety which was maintained throughout, as recommended by Laverty (2003 online). Participants were given the opportunity to ask questions about the process prior to the interview and reassured that the interview could be stopped at any point and the information obtained would be destroyed, if requested. Time was deliberately taken in ‘small talk’ to develop a relationship and help relax the participant by establishing some degree of trust and conversational rapport. Written consent was obtained (Appendix 3). The two interviews in the hospital were more difficult to carry out, the conversational flow was harder to establish and maintain. I was concerned that I was unable to facilitate these women to tell their story and tried to consider what it was they were not saying and look for the meaning in what was concealed, as suggested by Munhall (2007).

As research instrument, I needed to be immersed in the study and be part of the interview (van Manen 1990), as discussed in Chapter 4. Again, as a specialist cancer nurse, I was familiar with developing a conversation about potentially sensitive issues but just listening, in the research setting, was a challenge. The interviews were tape recorded. No notes were taken during the interview, to ensure full engagement with what the participant was saying but field notes were written immediately following. To commence the interview, one initial question was posed:

‘You recently had laparoscopic or ‘keyhole’ surgery for endometrial cancer – could you tell me about your experience of the surgery and what it meant for you?’

Gadamer (2004) suggested that no one can anticipate what will come out in the interview and the remainder of the interview was led by the direction of the conversation and responses from the participant but keeping the topic focused on the experience under study. A conversational flow was maintained during the
interview, with non-directive questions and responses. This allowed for more engagement from the participant while maintaining an awareness of what was being uncovered and what aspects of the experience needed probing, in keeping with Heideggerian phenomenology (Laverty 2003 online; Koch 1996). It was also important to pay attention to silence (van Manen 1990).

In phenomenological research interpretation of the data begins during the interview (Carpenter 2007a; Munhali 2007). As the interviews progressed emergent themes were developed and a sense of the depth of the information was becoming apparent. As I approached the twelfth interview, I felt I had reached the point at which no new themes were being obviously revealed and the depth of the data were sufficient to continue exploring the phenomenon with these participants, compatible with data saturation or data redundancy. A further two eligible patients had already been approached and given information by the medical team, these women were very keen to participate and so 14 women were interviewed in total.

Although all of the participants had undergone laparoscopic surgery on an endometrial cancer pathway, three women had become ineligible at interview because of the time lapse since surgery and the up and down staging of disease on final histopathology, as discussed. These three interviews produced detailed descriptions of the experience of laparoscopic surgery performed for endometrial cancer and the experience of these women did not distinctly differ from the others. There was more discussion about concerns, such as regret at having the treatment and anxiety about radiotherapy and prognosis. However, using Colaizzi’s (1978) framework these issues did not distract from the phenomenon, as discussed, and made me question the need for the inclusion criteria as described. On reflection, the study should have simply included all women who could communicate effectively in
English and had undergone laparoscopic surgery for endometrial cancer, as Colaizzi (1978:58) says 'anyone can serve as subjects provided they have experienced (the phenomenon) and are able to intelligently communicate it'.

Once analysis of the interview had taken place, each participant was asked to review the interpretation of their interview. The aim of this second interview was to reduce researcher bias but also allowed the participant to add more descriptions of the experience, especially after reflecting on the first interview. This is thought to lead to enriched data and increased participant satisfaction (Cohen 2000) and is in keeping with Colaizzi's (1978) framework for analysis.

5.7 Analytical Framework

One of the problems with using phenomenology is that the origins are in philosophy where there are few methodological signposts (Wilding & Whiteford 2005). Phenomenological research generates a large quantity of notes, tape recordings, jottings or other records, all of which have to be analysed to develop a rich description of the experience from the participants' point of view. Research analysis aims at reduction, categorisation and synthesis which involves taking the interview texts and producing something which is succinct and clear (Smythe et al. 2008). When conducting the phenomenological research it was important to consider over and over again the stories of the participants and what was said about the specifics of the phenomenon and the phenomenon as a whole (Wilding & Whiteford 2005). Since the data are viewed without a theory to guide the analysis, there is not necessarily a neat-falling into categories and there are many ways of linking between different parts of the discussions and observations. There are a range of methods to structure data analysis in phenomenological research, as well as arguments for not using any structure which may restrict the direction of the
experience (Ornery 1983). Anna Ornery (1983) compares and summarises three defined methodologies for the phenomenological approach, van Kaam, Giorgi and Colaizzi. In her description of Colaizzi’s framework she emphasised the detail with which Colaizzi structures the data collection, as well as using the perceptions of the researcher in the analysis. It was this description of the defined structure that appealed to me as a novice researcher and Colaizzi’s framework was also in keeping with my own philosophical position of understanding experience through the narrative and interpretation of our interactive lives, as discussed in Chapter 4. These were the reasons for choosing Colaizzi as the methodological approach in this study.

Colaizzi’s framework (1978) has often been associated with Husserl in nursing research (Dowling 2007; Mackey 2005; Smyth et al. 2008). However, Paul Colaizzi (1978) uses Heidegger’s articulation of the phenomenological method as the basis for his analytical framework and advocates the use of presuppositions to steer and develop the research rather than being bracketed or removed from the research setting. Colaizzi’s framework captured the elements required to give structure to this study, however, no single framework has rules that need to be rigidly adhered to and flexibility is required to adapt to unique research situations (Colaizzi 1978).

5.7.1 Paul Colaizzi

The preparatory phase of Colaizzi’s framework is a process of self reflection, documenting these reflections for reference during the analysis process (Colaizzi 1978). Colaizzi (1973), in his phenomenological study of learning, described a process of self reflection called Individual Phenomenological Reflection (IPR), where the researcher uses his or her own experience to create systematic reflections. Colaizzi (1973) considers this a necessary first step in the phenomenological
research process. The term IPR is not used in the subsequent framework Colaizzi described in 1978 but self-reflection remained the initial step in the process.

The purpose of this reflection is to become aware of one's biases and assumptions and to bracket them out, in keeping with the philosophy of Husserl or embed them in the interpretive process, in keeping with the philosophy of Heidegger (Laverty 2003 online). The seven steps described by Colaizzi (1978) were applied to the data:

- The participants verbatim transcript were read to get a sense of the whole
- Significant statements and phrases were extracted
- Meanings were formulated from significant statements
- Meanings were organised into themes
- The results were integrated into a rich and exhaustive description
- The fundamental structure of the phenomenon was formulated
- Validation was sought from the participants

Interpretation of phenomenological data is not considered to be a linear process. The hermeneutic cycle was the process by which I returned to the text for deeper meaning to derive a new interpretation, to expose the hidden and is connected with Heidegger's (1962) returning to the facts. The themes were not something that was said over and over again but an understanding that there was something seen that had significance (Smythe et al. 2008). The analysis arranged the findings according to themes drawn from issues discussed by participants. The aim was to be faithful to the participants but uncover a deeper understanding of the experience, while remaining aware of biases being brought to the editing and reduction.
5.8 Research Credibility

In positivist research, the reliability and validity of a study is the measure of scientific worth. Reliability refers to consistent and accurate representation of a population and validity refers to measuring what is intended to be measured. Qualitative research has traditionally been evaluated using these positivistic measures. Many researchers argue that it still should be but others suggest that a qualitative researcher views the world through a different lens and it would be inappropriate to apply positivist views of the world to qualitative research (Cutcliffe & McKenna 1999).

For Heidegger the most important aspect of sociological thought centres on the attempt to comprehend how we go about understanding the world in which we live and how we interpret our lives to make meaning of our existence (Cohen 2000). With this approach, research findings are not generalised to populations but build upon limited research and form a unique interpretation of events (Creswell 1994). Incorporated within the philosophy of gynaecological nursing is the concept of individualised care based on the physical, social, psychological, emotional, spiritual and educational needs of individual women (McQueen 1997). As such, gynaecological nursing emphasises the whole person and is in keeping with interpretive phenomenology which 'does not attempt to analyse compartments of human experience but study individuals within a cultural and contextual situation' (Hamill 1994:510). However, an interpretation of this study is expected to have meaning and value for others.

Interpretations are not considered to be right or wrong in the same way that qualitative theories are not right and wrong, just the most appropriate evidence until proven otherwise. Van Manen (1990:9) called interpretations 'plausible insights' and
suggested that there is no such thing as an omniscient perspective only a personal one. Despite all interpretations being potentially valid, the challenge is to make sure they are as reflexive and rigorous as possible (Wilding & Whiteford 2005).

Cutcliffe (1997) suggests that qualitative methodology needs to be rigorous and systematic with the emphasis on the processes and meanings. There are many ways described to establish credibility in a qualitative research approach. Burnard (1991) suggests researchers should use a colleague to analyse the data independently and although there are numerous theoretical arguments against this (Cutcliffe & McKenna 1999), it allows an experienced researcher to verify the categories and themes developed by a less experienced researcher. Guba and Lincoln (1981) recommended that researchers leave an audit trail as a record of the events, influences and actions of the researcher. The idea of an audit trail is similar to that used in financial accounting where audit provides a way to exclude the possibility of error or fraud but it also allows another researcher to follow the decisions and deductive process of data analysis (Koch 2006). Returning to the participants is also described as a method to enhance the credibility of a study (Guba & Lincoln 1981) and forms one of the recognised steps in Colaizzi's (1978) framework for rigorous analysis.

This project was carried out with supervision from an experienced qualitative researcher to support the analysis of the data. During the course of the study a research diary with details of decisions and deductive processes was maintained. Returning to the participants was employed as part of Colaizzi's (1978) framework and the findings are presented using the words of the participants. These measures were taken to ensure rigour and demonstrate credibility of the study.
However, it can be argued that, for phenomenological research, the data are credible if others can recognise the experience as one they have had or could have (Crotty 1996; Dowling 2007; Guba & Lincoln 1981; Paley 2002) and are considered meaningful to practitioners and managers in terms of their experience (Cutcliffe & McKenna 1999). This has been recognised as the 'phenomenological nod' (van Manen 1990:27) and as Smythe et al. (2008:1393) point out that when we read a poem we do not ask 'can I trust the process by which it is written' but consider if the meaning could have any applicability in our own life. The overall aim was to demonstrate rigour which will enhance the scientific credibility of the study but to produce a description of the experience that had meaning for others.

5.9 Summary of Chapter

Face-to-face interviews were used to collect qualitative data from 14 women who had experienced laparoscopic surgery for endometrial cancer at two UK cancer centres. Ethical approval was obtained for the recruitment of women with low-risk disease, who were able to communicate in English and had their surgery less than a year previously. All women were recruited on these criteria but three became ineligible at interview, however, all data were used in the final analysis. The interviews were taped and the transcripts analysed using Coiaizzi's (1978) analytical framework. Supervision with an experienced qualitative researcher, the keeping of a research diary, returning to the participants for validation of the interpretation and reporting the data using the participants own words were methods employed to ensure rigour and credibility in this study using a qualitative approach.
6.1 Introduction

This chapter presents a detailed description of the process of data analysis used in this study. Analysis involves the breaking up of something which is complex into its various elements (Oxford English Dictionary (OED) 2009 online). Research data analysis, therefore, can be seen as the process by which a complex phenomenon is broken up and the raw data are transformed into usable information. Data analysis, in this study, involved the Tape-Transcribe-Code-Interpret (TTCI) cycle (Lapadat & Lindsay 1999) but began with an exploration of my personal preconceptions and bias as researcher in this study, in keeping with phenomenological methodology and Colaizzi's (1978) framework. This chapter is laid out following the steps described by Colaizzi (1978) and will provide details of the decision making process to demonstrate the analytical decision trail, discussed in Chapter 5.

6.2 Preparatory Phase

The preparatory phase of self-reflection involved developing an awareness of my preconceived notions and bias about laparoscopic surgery for endometrial cancer. To do this I needed to recognise that ‘phenomena are inconceivable except under the condition that they are contacted or experienced or lived through’ (Colaizzi 1973:28). It is this first lived-through experience that defines the fundamental understanding or existential a priori and it is this that individual phenomenological reflection (IPR) seeks to acknowledge (Colaizzi 1973).

I considered my experience as a specialist nurse involved in the delivery of a service, working with laparoscopic and non-laparoscopic cancer surgeons and managing the care of women with gynaecological cancer. This reflection led to the
development of a formal statement that represented my presuppositions as a specialist nurse, about laparoscopic surgery for endometrial cancer:

Women who have laparoscopic surgery for endometrial cancer are a chosen minority who happen to meet a specialist laparoscopic surgeon on their preoperative cancer journey. The development of laparoscopic surgery has been driven by the desire of surgeons to ‘progress’ their craft but women offered this surgery are keen to have the procedure performed in this way. Women who have had laparoscopic surgery for endometrial cancer are generally quick to mobilise and become self-caring because of physical flexibility and low levels of pain. A short hospital stay equates to minimal contact with healthcare professionals and clinical services.

According to Colaizzi (1978), the aim of the phenomenological interview is to uncover the participants’ experience of the phenomenon as distinct from their theoretical knowledge. My experience as a nurse would also contain elements of theoretical knowledge but I tried to consider my own experience of laparoscopic surgery for endometrial cancer, that is, what I had seen and felt for myself during consultations, in multidisciplinary team meetings, in tumour working group meetings and as part of nursing care. These reflective statements provided me with a basis on which to consider the responses and my interaction with the participants as described by Colaizzi (1978). This is in keeping with Heideggerian Phenomenology where the researcher recognises prior knowledge and does not attempt to bracket it out of the research setting, as discussed in Chapter 4.

6.2.1 Participants

Data from all 14 participants were analysed,
6.2.1.1 Descriptive Statistics

The age of the participants ranged from 43 years to 88 years (mean 62 years; SD 11.5) which was in keeping with the epidemiological data, discussed in Chapter 2 and UK cancer statistics for 2005, where most women diagnosed with endometrial cancer were in the 55 years to 74 years age group (CRUK 2009b online).

The participants in the study demonstrated some of the high risk factors associated with endometrial cancer, discussed in Chapter 2: Six of the participants would be considered obese to WHO definitions (World Health Organization (WHO) 2009). One participant had been refused surgery at another hospital because of her morbid obesity. Seven participants were diabetic and six were over the age of 65 years.

Seven of the participants were in paid employment, one was self employed, five were retired from paid employment and one participant had never worked outside the home. Six of the participants lived with a partner and/or family member and eight participants lived alone. Two participants had lost a partner to cancer.

Prior to treatment, four participants described having symptoms for less than a month, five described symptoms for between one month and six months and five reported the presence of symptoms for over a year. The waiting time from diagnosis to operation, ranged from just a few days to seven weeks but most of the participants in this study were treated within two weeks or less. The longest wait involved a transfer from private to NHS care and one participant chose to delay her treatment for almost two months.
Nine of the participants had a hospital admission for surgery that lasted four days, four were in hospital for five days and one was an in-patient for seven days.

6.2.2 Interviews

The interview time ranged from 40 minutes to 80 minutes (mean 61 minutes; SD 14.8) (Table 6.1). The analytical process began during the interviews with my interpretation of what was being said and my attempts to clarify the information given and explore any reference made to the issues identified in my phenomenological reflection. Each interview informed the next in an evolving analytical process. The interviews were tape recorded to facilitate formal data analysis.

6.2.3 Transcription

Transcription is the act of presenting the original oral language in a written format (Bird 2005) and is a common method of managing oral data obtained in interviews but it is not without its own controversy and epistemological assumptions (Lapadat & Lindsay 1999). Transcription often aspires to be verbatim, that is word-for-word, and it is commonly assumed that verbatim transcription is a transparent, direct reflection of the reality of the interview. However, language itself is not transparent (Lapadat & Lindsay 1999) and the reality of a multi-dimensional event, such as an interview, is naturally reduced when represented onto a two-dimensional page (Bird 2005). Lapadat and Lindsay (1999) also suggest that the researcher and transcriber make choices about what to transcribe and how it is represented. In addition to the actual words spoken, the interview contains silences, body language, facial expressions, sighs, coughs, hesitations, tone, inference, etc. Poland (1995) argues that, transcription is an interpretive activity and no transcription will ever be complete.
My initial aim was to carry out the transcription myself, which would have allowed me to become immersed in the data and relive the interview during the transcription process. It has been argued that researchers should carry out their own transcription but this is often not practical or cost effective and the value is unproven (Ball 2009; Bird 2005; Lapadat & Lindsay 1999; Poland 1995). I found the process of typing the tapes disjointed and error laden and considered the possibility of only transcribing what was relevant to the study, as described by Bird (2005). However, I felt unable to decide the relevance of the data at that point.

For me, the most valuable part of the initial transcribing process was listening to the voice of the participant and reliving the interview experience through sound. The data were primarily held on tape in the recording of the interview and the transcription represented a convenient way to manage and store that data. It was through listening to the tapes that the voices of the women became infused with the meaning as experienced during the interview. This type of connection with the interview is recognised and has been described by Psathas and Anderson (1990) and Munhall (2007). It was clear at this point how the interview had already been transformed from the one that had been experienced, a live social exchange and interaction, to the one on tape, as Kvale (2007:93) described 'a first abstraction from the lived bodily presence of the conversing persons, with a loss of body language as posture and gestures'.

It has also been suggested that audiotapes can be analysed by listening and reviewing and not transcribing (Halcomb & Davidson 2006; Lapadat & Lindsay 1999; Munhall 2007) but managing large amounts of data and demonstrating decision making can be difficult with this method. Listening and keeping in touch with the spoken interview was the most important thing for me and because I could not
manage without the verbatim transcription, the remaining tapes were professionally transcribed.

Systems for transcribing talk, where symbols are used to describe characteristics such as silences, pauses, intonation etc, are called transcribing conventions. A researcher can chose to use a recognised convention, such as the Jefferson Transcription System (Lapadat & Lindsay 1999), or create a convention specific to the needs of the study. A simple convention was used in this study where P represented participant speech and R researcher speech, with common English grammar (see Appendix 4 for transcription examples). Keeping in touch with the oral data and being the researcher present in the interview, meant I did not have to concentrate on a more detailed transcribed representation. Each of the transcriptions was checked against the taped recording to reduce error and act as a reliability check, as recommended by authors such as Poland (1995) and Kvale (2007).

6.2.4 Sorting and Transforming the Data

Word processing systems allow text to be rapidly edited and easily manipulated and so the interviews were transcribed into the computer word processing programme Microsoft Word. Once the interviews were transcribed, the typed data were available for structuring as part of the analytical process.

The time taken for each interview and the volume of data generated are displayed in Table 6.1. These figures are presented here to demonstrate the practicalities of conducting the interviews, giving an indication of the size of the data management task. However, it is no indication of the depth or quality of the individual interview.
Table 6.1 Interview time and transcription details: Laparoscopic surgery in endometrial cancer.

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<th>Time in minutes</th>
<th>Number of pages</th>
<th>Word count</th>
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</table>

*font size 12, single spacing.

6.3 ‘Read All of the Subjects’ Descriptions’

The first procedural step in Colaizzi’s (1978) framework was to read all of the participant’s descriptions or protocols (Colaizzi initially uses the term ‘subjects’ and goes on to use the term ‘co-researcher’ but in keeping with the concept of a research partnership and without confusing the roles within the study, I chose to use the term participant). This step was concerned with getting a sense of the interviews as a whole; to begin to make sense of them as a complete study. The analysis had begun during the interview and continued through the transcription but it was at this stage that the analysis was structured. This proved to be a highly reflective process and ensured that saturation point, where no new data were being introduced, as discussed in Chapter 5, was achieved. It would have been possible to return to the participants or recruit more participants if the data were lacking depth.
Although the interviews had already been altered and interpreted in the process of being transformed into a recording and then a written document, I maintained my connection to the original experience of the interview by continuing to listen to the tapes while reading the transcriptions. Once a sense of the whole data set had been developed, the process of structuring the data, to demonstrate patterns or themes and organise them into coherent categories, began.

6.3.1 Managing Textual Data

There are several ways to organise qualitative data, from highlighter pens and Post-It notes, to specially designed software packages (Fielding 1993 online). Qualitative analysis is concerned with interpretation and not the technical aspects of data management and manipulation (McIntyre 1998). However, with nearly 200 pages of data, a system was required which would organise the data in a way that would allow me to make sense of it, while preserving the complexity and facilitating the connection of one piece of information with another. It is this need to track data that has resulted in the development of qualitative computer software packages to 'augment our own human senses' (Meyer & Avery 2009:91).

Since I had already committed the interviews to an electronic format, by way of transcribing into Microsoft Word, it was logical to continue electronically with data management and storage. The arguments that computer packages pose a potential threat to the craft of qualitative analysis, especially in more interpretive research such as hermeneutics (Fielding 1993 online), was, for me, unconvincing. There are many manual methods of identifying and coding themes. For example, Morse and Field (1996) described the sociologist Erving Goffman using a system of cards, which described themes, being placed in brown envelopes that became heavy when a theme was significant. However, this could be replicated on a computer by placing
identified themes in a computer ‘box’ which, when it becomes ‘full’, suggests significance. The concept of losing touch with the data through the use of computers, as discussed by Burns and Grove (2006), might be considered parallel to literary authors who have been slow to use the typewriter or word processor for fear of disconnecting with their words (Honeycutt 2004). However, not many contemporary authors would use a typewriter and few, if any, would use pen and paper.

Shaha and Cox (2003) argue that computer supported analysis would not suit a research design using Heidegger’s Phenomenology but do go on to reduce narrative texts, comprising of participants’ significant statements, according to Coiaizzi’s (1978) framework. Although they do not describe the process of managing the ‘substantial’ amount of data, these statements exist in a written format and it could be argued that these statements can be managed using any system that allows the researcher access to, and free movement between them. In principle, any computer package that helps the researcher to move around the data and track identified themes would be acceptable to use.

Word processing packages such as Microsoft Word have been used to manage relatively small amounts of qualitative data (Hahn 2008; Morse 1991; Taylor-Powell & Renner 2003 online). The features of word can be used to organise the data and facilitate efficient qualitative coding (Hahn 2008). However, word processing packages also have limitations and tracking and cross-checking data can be difficult, especially across fourteen interview protocols containing 129,818 words (Table 6.1).

Specialist software packages such as NVivo are increasingly used in qualitative data analysis. NVivo manages data by allowing the researcher to assign themes and ideas, called nodes. However, working with and coding textual data on
Microsoft Excel is part of my current role and is the way that free text qualitative data in Patient Safety Incident reports are currently analysed at the National Patient Safety Agency. Microsoft Excel facilitated data management according to Colaizzi’s (1978) framework and despite it being primarily associated with numerical data; it has also been suggested as a valuable tool for qualitative researchers (Fielding 1993 online; Hahn 2008; Meyer & Avery 2009; Taylor-Powell & Renner 2003) which has been used by other qualitative researchers (Aujoulat et al. 2007). According to McIntyre (1998:82) spreadsheet and database software is now ‘so flexible and powerful that it can be adapted either to quantititative or qualitative analysis’. Using a computer allowed me to maintain the pre-analysis integrity of the data and made the analysis more accessible to others, providing an effective audit trail.

6.4 ‘Extract Significant Statements’

Extracting significant statements involved identifying statements which related to the experience of laparoscopic surgery, which were ‘cut’ from the electronic copies of the protocols, ‘pasted’ into the Excel spreadsheet and assigned to the relevant participant. Colaizzi (1978) recommended that event specific statements are transposed to a more general formulation; for example, one participant’s sentence ‘I mean I had a shower in the morning’, was rendered as ‘able to shower the day after the operation’. This move from the specific to the more general was also used by the phenomenological researcher van Kaam (1959). Although, this process of reduction

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helped with the coding of statements, it would have been easy to lose the ‘voice’ of the participant as contained in the verbatim statements.

Colaizzi (1978) also recommended that, where protocols contain, or nearly contain, the same statements, these repetitions can be eliminated. However, sometimes the words chosen held significance that became apparent only on returning to the text and were often reviewed and reassigned during the iterative process of hermeneutic analysis. Creating a column in the Excel spreadsheet headed ‘verbatim significant statements’, followed with ‘significant statements’ (Figure 6.1), was the mechanism used to reduce the volume of data but retain the ‘voice’ of the participant in an easily searchable format. Over 1000 verbatim significant statements were initially ‘cut and paste’ into the Excel spreadsheet. Verbatim statements that represented the same significant statement were merged, leaving a data sheet of 699 items, representing 699 significant statements from the 14 participant protocols.

**Figure 6.1:** Excel spreadsheet showing participant identifier, verbatim statement and significant statement.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Verbatim statements</th>
<th>Significant statements</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>everything would be alright, I would have been absolutely astounded if it wasn’t, I wasn’t 1001 bothered or anything.</td>
<td>feeling looked after and taken care of</td>
</tr>
</tbody>
</table>

**6.5 ‘Formulate Meanings’**

When formulating meanings, the phenomenological researcher engages in what Colaizzi (1978:59) calls ‘creative insight’, leaping from what the participants have said into an interpretation of what they mean. Colaizzi (1978) warns that it is important to maintain connection with the original protocols, discovering what is hidden, going beyond the original data but remaining with it. This was expressed by
Heidegger (1962:58) as letting 'that which shows itself be seen from itself in the very way in which it shows itself from itself' and is considered by Dreyfus (1991) to be a fundamental concept of phenomenology that encompasses both Husserl and Heidegger.

This was possibly the most difficult and least structured phase. It involved what Colaizzi (1978:59) acknowledges as 'ineffable'. In the example being used in Figure 6.1, which referred to the medical team, I took 'feeling looked after and taken care of' and formulated 'transfer of responsibility to the doctors'. The formulated meanings were then given a new column (Figure 6.2). This process was completed for all formulated meanings. Some of the different significant statements were formulated with the same meaning but these were retained in the spreadsheet if attributed to different participants. It was at this stage that repetition within a protocol could be easily identified and removed. There were 185 different formulated meanings (see Appendix 5 for more examples).

6.6 'Aggregate Formulated Meanings into Clusters of Themes'

The next step involved organising the formulated meanings into clusters of themes which were common to all of the subject protocols. This required a second leap of the ineffable 'from what is given in the meanings to themes given with them' (Colaizzi 1978:59). However, with a data set of 185 formulated meanings, this was carried out as a two stage process, in which themes were identified for each
formulated meaning within the protocols and then clusters of themes were identified across the protocols. This created a series of sub-themes which were then incorporated into a main theme. Colaizzi (1978) recognises the need for flexibility when using the framework and a multi-step approach to Colaizzi's framework has been adopted by other phenomenological researchers (Haase 1987; Paavilainen & Astedt-Kurki 1997).

In order to validate these themes, the original protocols were checked to ensure that there was nothing in the original protocol that was not accounted for in the themes, or anything in the themes, that was not accounted for in the protocols, as described by Colaizzi (1978). By carrying out the process of attributing themes to the formulated meaning in two stages, I was able to keep track of themes and was not tempted to prematurely dismiss those which did not fit, or that I could not initially validate, which is something Colaizzi (1978) warns against. Using the filter and split screen functions of Excel made viewing and cross checking large numbers of themes relatively easy to manage.

Fourteen sub-themes were identified across the 185 formulated meanings. These sub-themes were used to develop the clusters of themes that could be seen across the 14 protocols. Five phenomenological theme clusters were identified and described as: having cancer, information and support, independence, normality and transfer of responsibility to the surgeon. The sub-themes and themes representing the phenomenon of laparoscopic surgery for endometrial cancer as experienced by women who have undergone the procedure, are graphically represented in Figure 6.3.
Figure 6.3: Fourteen sub-themes and five themes representing the phenomenon of laparoscopic surgery for endometrial cancer as experienced by women who have undergone the procedure.

6.6.1 Numerical Representation

- Over 1,000 verbatim statements
- 699 significant statements
- 185 formulated meanings
6.6.2 Thematic Analysis

The themes and sub-themes were often overlapping and interconnected. They represented patterns of description bound within the experience and not separate from it and constituted the components of the whole. My development and understanding of the themes and sub-themes changed constantly during the analytical process. For example, a sub-theme of feeling positive was identified in relation to the theme of having cancer but this did not accurately represent the underlying meaning which was more about a consideration for the future, so this was reconceptualised as the future. However, on further reflection these statements represented a fear of the potential consequences of the disease, a fear of cancer. The examples which demonstrate each theme and sub-theme are presented in Chapter 7.

6.7 'Integrate the Results into an Exhaustive Description'

The results were integrated into an exhaustive description of laparoscopic surgery for endometrial cancer. This represents a narrative integration of the themes and sub-themes. This exhaustive description represents the findings of the study and is discussed in Chapter 8.

6.8 ‘Formulate the Statement of the Fundamental Structure’

The fundamental structure of laparoscopic surgery in endometrial cancer represents the integration and synthesis of the exhaustive description formulated into an unequivocal statement and is presented as a summary to Chapter 8.
6.9 'Validation with Participants'

A final validation step involved returning to the participants of the study to confirm the findings. Colaizzi (1978) suggests that this can be a single interview or a series of interviews. Although the participants had been prepared and consented to a second interview, I was conscious of the time the participants had already given to the study and the difficulty with which some interviews had been arranged around work and childcare (or grandchild care). In a phenomenological study of courage in chronically ill adolescents, Haase (1987) successfully used telephone interviews to carry out the validation step described by Colaizzi (1978). I decided to offer the participants the choice of a second interview in their own home, in the hospital or over the telephone. All but one chose the telephone option. The validation interviews were arranged for a convenient time and took between 20 minutes and 30 minutes to complete.

Crotty (1996:171) argues that participants (using the term co-researchers) need to engage in phenomenological seeing in relation to their experience and as a group be able to compare and contrast the individual descriptions. Crotty goes on to suggest that the level of insight required to be a co-researcher is that of phenomenologist and 'not everyone is equal to the task'. Therefore, in Crotty's view co-researchers should be 'disciplined people' who are able to transcend their taken-for-granted assumption and should be carefully chosen. However, using Colaizzi's (1978) framework, it is possible to be more inclusive and enable all those who have experienced the phenomenon to share in the phenomenological seeing. Using the validation interview, it was possible to demonstrate the individual and collective interpretation and to confirm with the participant the validity of my interpretation of their interview.
The 14 validation interviews consisted of describing the individual formulated meaning, which had been ascribed to the participants’ protocol statements, together with the findings of the study so far, based upon the group experience. This proved to be more difficult than anticipated and required an explanation of the formulated meaning rather than just presenting a list. Where there was discussion, notes were taken of what the participant said with regard to the specific formulated meaning. A further column was created in the Excel spreadsheet and elaborations, confirmations and amendments were added as appropriate. These were then incorporated into the final analysis.

6.10 Summary of Chapter

Colaizzi’s (1978) framework was used to inform and analyse the data collected in the 14 tape recorded interviews required to reach data saturation. The interview tapes were transcribed verbatim and significant statements were interpreted into formulated meanings and organised using Microsoft Excel. Fourteen sub-themes were identified as representing five theme clusters; having cancer, information and support, independence, normality and transfer of responsibility to the surgeon. Identification of the themes led to the formulation of the statement of the fundamental structure of laparoscopic surgery in endometrial cancer. A second interview was carried out to validate the findings, in keeping with Colaizzi’s (1978) framework.
7.1 Introduction

This chapter presents the analysed data, which represents the exhaustive description of the experience as described by Colaizzi and discussed in Chapter 6. Presenting phenomenological data is not straightforward, as Patricia Munhall (2007:199) states 'there are many different ways to present your findings... for which there is no formula'. She suggests choosing a style that will effectively communicate the understanding of the particular meaning.

Having remained close to the individual participant's story, with the continued listening of the interviews and returning to the protocols, it seemed appropriate to present the data in the form of the individual stories of the participants before considering the study as a whole. This is a technique practiced by many phenomenological researchers (Munhall 2007). However, having followed Colaizzi's model it also seemed logical to present the data according to the extracted themes and sub-themes, giving evidence to demonstrate the 'creative insight' discussed in Chapter 6.

In addition, the participants described intimate details of their lives and concerns about their care; things that family, friends and other healthcare professionals were unaware of but which were important to the study. Relaying each participant's story in the way described by Munhall (2007) could potentially make the participants identifiable. Therefore, the findings have been presented under the headings of the identified themes and sub-themes. Participant verbatim statements were used to demonstrate the themes and were attributed to each participant by the participant number (P1001 to P1014). However, where there were specific references to a
singular participant, such as the participant who had private care, the participant who had premalignant disease or the oldest/youngest participant, then the participant number was not included and the symbol P* used to ensure confidentiality. For the same reason, a participant number was not assigned to any presentation of demographic data. Presenting the data by creating a narrative with the themes and sub-themes relays how the experience was reduced for analysis and recreated into a new interpreted whole. This chapter will conclude with a description of the fundamental structure of laparoscopic surgery in endometrial cancer, as discussed in Chapter 6.

7.2 Theme: Having Cancer

The stories the participants told about their experience of laparoscopic surgery were interwoven with their experience of having cancer. Having cancer featured as a theme for all of the participants in the study. Having cancer was broader than the final diagnosis on histopathology, it included the initial diagnosis, their hopes and fears and how they were managed through healthcare services. It incorporated the sub-themes; a cancer diagnosis, fear of cancer and speed of treatment and was expressed in 76 of the 699 significant statements, across 23 of the 185 formulated meanings.

Having cancer was bound so intricately within the story of the laparoscopic surgery that it fundamentally shaped the experience. Some of the women found it easier to use the word cancer than others but it remained the ‘missing’ word in many of the statements across all of the protocols.

7.2.1 Sub-theme: A Cancer Diagnosis

All of the participants in the study readily recalled being given the diagnosis of cancer as a feature of their experience. Nine of the participants expressed a sense
of knowing that they had cancer or that something was seriously wrong before the
diagnosis was confirmed by the medical team. As one participant, in relation to her
clinic visit accompanied by her daughter, described:

‘they did call me back, Mr., it wasn’t Mr. (named surgeon) it was one of his
colleague and, and, um they told, they told my daughter about, but they told.., my
daughter went with me and they say what I have but I suspect something like that
before’ (P1002:p32).³

Another participant expressed this several times:

‘I knew there was something wrong but I just knew’, ‘I thought he’s telling me,
he’s telling me what I know’, ‘I thought: that’s it, I know I’ve got cancer’
(P1010:s520).⁴

Even when reassured that there was nothing wrong at a previous consultation,
for some of the participants there remained a sense of knowing that this wasn’t the
case, for example:

‘Because I still felt that, even though I know nothing about cancer, my sister had
cancer, it was breast cancer she had, um, but I didn’t feel right (R: okay) even
though I felt nothing (R: yeah) but I just felt there was something else there and I
couldn’t be convinced that there was nothing there’ (P1012:p177).

³ ‘p’ refers to the protocol line number.
⁴ ‘s’ refers to the spreadsheet row number.
This sense of knowing was expressed alongside other emotions such as shock or disbelief at the diagnosis but two participants described not having considered the possibility of cancer before the diagnosis. One participant expressed her shock by saying:

‘it was more serious than I had anticipated it could ever be’ (P1008:p54).

Both of the participants who discussed not having expected a cancer diagnosis, had experienced abnormal vaginal bleeding which had been investigated and treated in the past.

How participants approached their diagnosis and how they immediately reacted to the diagnosis was dependent upon other factors such as past experience or expectation but the diagnosis of cancer remained a discrete sub-theme and a pivotal event within the experience.

### 7.2.2 Sub-theme: Fear of Cancer

All of the participants expressed some degree of fear about cancer. Descriptions in this sub-theme were as succinct as ‘cancer is a silent killer’ (P1002:p408) and ‘as soon as you hear the word tumour’ (P1006:p28), as well as evoking a complete picture, such as the one created by a participant too frightened to even take a seat in the consulting room or wait another second to be told her diagnosis:

‘have I got cancer then? And he went “can you sit down”, ‘I’m stood there, shaking and I said “oh, was it cancer?”’ (P1010:s533).

The participants described associating cancer with death and the possibility of dying from the disease or the treatment, for example:
'I'd left a, left instructions with certain people about things...in case I die under the operating table' (P1010:p207).

The fear of cancer also incorporated fear of the words associated with cancer and was described by some participants but was also evident in the avoidance of the word, as discussed, or difficulty in disclosing the diagnosis to others, for example:

'I couldn't even say that word cancer', 'cancer, it frightens the life out of me' (P1005:s204) and 'although at the back of my mind I had an inkling that it wasn't right and it could be, it could possibly be...,(R: right)' (P1004:p27) and 'I couldn't tell her over the phone, I knew that I would cave in' (P1010:p229).

Fear of cancer because of an association with pain was also expressed in this study by a participant who said:

'I always dreaded when I heard anyone had cancer I always used to think, oh the dreadful pain' (P1007:p33).

This fear of cancer led participants to express their desire to remove the cancer, to be rid of it, for example:

'all I wanted to do was get rid of it', 'it was cancer, I thought oh my God...I want it out, get rid of it, you know' (P1005:s239) and 'anyone who has got a growth, you just want it away from you' (P1001:p122).

It was almost as though the cancer was something which was not part of them, something independent and not normal body cells which were behaving in an abnormal way. The use of words like 'sinister' (P1001:p23) and 'silent killer' (P1002:p408) almost personified the cancer, giving it some form of intention or
conscious purpose. This desire to be rid of the cancer led to feelings of having no choice about treatment:

'so if it was cancer, there was not much else I could do' (P1011:p64) and 'basically you know if you've got a cancer you want it to be removed and so I had to have the surgery' (P1013:p135) and 'there was no choice, because at that stage it was precancerous' (P1011:p63) and 'bring this cancer out with the womb' (1001:p70), where the surgeon described the trade off for removing the cancer was to also remove the womb.

Fear of cancer was also expressed as denial. Denial was described at two points in the experience, denial of the possibility of having cancer before the diagnosis was made and denial of the cancer following the diagnosis. Denial before diagnosis was used as a mechanism to remain in the world of the well and not to accept the possibility of cancer despite sensing that a bodily change had occurred. Four of the participants expressed denial at the possibility of having cancer. In one example:

'I just pretended nothing was happening and I knew that there was something wrong but I thought it goes and comes, it's nothing serious, that was what one illogical part of the brain was telling me but I knew logically' (P1010:p22).

In another example:

'I just went to pieces then and forgot all about it, and it was only because my sister kept on about it, all the girls at work, you should do this, you know, you're, you're over fifty now, so I was, so I thought right' (P1005:p22).
Denial for some participants co-existed with a sense of knowing that something was wrong and in expressions of being shocked at the time of diagnosis. Denial was also seen once the diagnosis had been made and the cancer was rationalised and reconceptualised by the participants as somehow different, non-malignant (that is, no longer able to spread) and therefore not 'real' cancer. Despite knowing and accepting her diagnosis, when one participant was introduced to the Macmillan nurse she described being 'jolted' and it 'making that cancer a big thing' (P1001:p264). It was as though her cancer without a Macmillan nurse was somehow different, less significant, than her cancer with a Macmillan nurse. The same participant articulates this sense of ambiguity about what cancer is or means, by saying:

'It's cancer but that doesn't bother......, it doesn't bother me at all. Might have done if it was' (p567).

In a similar example, another participant described her reaction when the referring surgeon gave her the diagnosis and then implied that it was not actually cancer:

'I said I didn't think I had it, and all this, and she said, you haven't you know' the participant goes on to rationalise this by explaining that the cancer was 'just at the outside so I was really lucky it never sort of, hadn't gone any further' (P1014:p32).

The fear of cancer was not static or predictable and could be influenced by friends, family or healthcare professionals. What was said and how the diagnostic information was imparted had the ability to influence the participant's perception of the cancer, for example:
"I wasn't concerned about the fact that I'd been diagnosed with cancer once I knew that it was, you know, something that could be sorted out" (1003:p644) and 'that (named surgeon) could tell me I'd got cancer without me going up the wall, I thought was quite a good thing in his favour, he said "yes it is cancer" and I thought, but he, he, I thought he did it so well" (P1006:p16) and when recalling the surgeon giving the diagnosis with the family present one participant recalled "oh no, no, no you come in" and they were sort of chatting together, he was chatting to them and telling them, you know "it was really, really nice when they told me about it' (P1007:s332).

As part of the fear of cancer and coping with the diagnosis, there was a sense of considering the future. This consideration for the future could be expressed as a sense of feeling positive:

'I'm going to be, this is going to be okay for me' (1010:p209) and 'I know it's gone and that's it' (1005:p674) and in the description 'I had the all clear' (1001:p72).

Alternatively, it could be seen as concern about recurrent disease:

'I've been more worried since, thinking it might come back' (1007:p236) and 'that lady got a problem and after she, she's died' (1008:p327).

As discussed in Chapter 2, endometrial cancer has a good overall prognosis, with most women being cured from the disease (Parkin et al. 2005). This information was relayed to the women in consultations and obtained from other sources outside the hospital. The sense that the cancer was curable was expressed in terms of being able to remove the cancer and being grateful 'that it could be removed' (P1003:p37) or in the sense of what could have been if the cancer had not been treated so promptly:
7.2.3 Sub-theme: Speed of Treatment

In Chapter 2 the concept of rapid treatment for cancer was discussed in relation to Government guidelines designed to improve cancer outcomes in England (Department of Health (DH) 2000b). During the analysis, evidence of the impact of rapid treatment could be identified, for example, 'it all happened so quickly' (1006:p402) and 'it's the speed of what's happened' (1008:p50). There was a sense of a mixed reaction to the speed of the treatment. For example, one participant said she was:

'delighted (by) the fact that it was a week from sort of start to finish' but also acknowledged that this meant that the hospital 'weren't quite able to do the sort of, the, all the necessary pre-testing and pre-preparation' (1003:p50).

Another found the speed of the treatment frightening but also reassuring:

'well it's all so scary but then they're getting it quick, aren't they?' (P1010:p712).

Because of the rapid treatment, preoperative information could be confusing and inconsistent, for example one participant would have been taking HRT up to a week before the surgery if she had not refused the initial date given but was told to stop HRT for a month when the operation date was changed. The participants associated the need for rapid treatment with having cancer. As one participant pointed out, she would probably have required a hysterectomy because of her symptoms but it 'wouldn't have been so soon' (1008:p477).

However, one participant found the pressure to have the surgery quickly made the process even more difficult:
‘I was absolutely gob-smacked by that...perhaps I ought to have it really, really quickly’ (P1009:p52).

7.2.4 Summary of Theme: Having cancer

Having cancer was expressed in relation to being given a cancer diagnosis and the fear of cancer which shaped the participants reactions to the treatment and services offered. Denial played a part prior to the diagnosis of cancer and also in coping with the diagnosis once it had been made. The speed with which the treatment was planned reinforced the threat that the cancer posed but the participants developed a sense of considering the future, both what would be and what could have been. How the diagnostic information was imparted or interpreted had the ability to alter the experience. A description of the formulated meanings and sub-themes for the theme having cancer are displayed in Appendix 6.

7.3 Theme: Information and Support

Through the interviews and analysis a pattern emerged regarding the need for information and support but this was highly individual and based upon the life experiences of the participants. Laparoscopic surgery was not performed in isolation; it was performed for women with suspected cancer who wove the story of their experience alongside the story of their individual lives. Information emerged as a theme during the first interview in relation to what information was given by the hospital team and broadened to incorporate many different aspects of information such as, sources of information, quality of information and lack of information. The breadth of issues in this sub-theme represents the diversity of the needs of the participants with regard to information in healthcare in general and specifically in cancer. The information needs of the participants reflected their past experience,
their knowledge, their personal circumstances and their personality and were situated in the context of their individual lives.

This theme incorporated the sub-themes, knowledge and understanding, preconceptions and relationships. Information and support was expressed in 133 of the 699 significant statements and across 44 of the 185 formulated meanings.

7.3.1 Sub-theme: Knowledge and Understanding

Prior knowledge and past experience influenced the way in which the women approached and experienced their cancer and their surgery. Most of the participants referred to a lack of knowledge regarding cancer, surgery and the process of being in hospital, for example:

‘you don’t know much about cancer’ (1003:p38) and ‘but nobody in my family’s ever had hysterectomy at all, nobody’ (P1005:150) and ‘none of the nurses at first said you know, get, told me what to do’ (1006:p55).

It was also pointed out that this type of knowledge was not something you would expect an individual to have:

‘it’s a learning curve for me, it’s not somewhere where you’ve been before, you don’t know what to expect, you’re not taught it by your mothers, you don’t expect to have a hysterectomy’ (P1009:p29) and ‘I didn’t know, so, um, you know, it probably seems incredibly ignorant’ (1003:p423).

However, what was expressed as a lack of knowledge created a gulf between the information that was formally given and that which was required by the participants. For example, one participant, who, despite being postmenopausal and through ‘the change’, did not understand the implication of surgery on her
menopausal status and this was not discussed with her. She perceived this as a lack of information, an unmet need:

'like hormones...and they don't tell you anything like this, what, am I, am I still going to carry on going through the change' (1005:p72).

Another participant had been told to stop taking HRT prior to surgery but not told the effect this might have on her. When she started having palpitations as a result of stopping her HRT she became anxious and then angry that she had not been informed:

'when I gave it up I started having heart palpitations, not being able to sleep at night...nobody told me about, nobody at all' (1009:p548).

Information regarding what to expect after the surgery was also seen to be lacking, with participants not being informed of the intravenous fluids, catheter or vaginal packing that they would wake up with postoperatively:

'I'd been told about the packing and I thought the girl in the pet shop was having me on...I wish they'd told me, because I still thought she was having me on' (P1010:s541) and 'what's this? Tubes and oh, my God, what's all this' (P1005:p112).

Information that was given was described as difficult for the participants to understand. For example, one participant described being told that she had 'atypical hyperplasia cells' and went on to explain:

'which was all new wording to me, um, I didn't know anything' (P1009:p47) adding 'to be presented with something that says bilateral salpingo-oophorectomy
is, is a hell of a mouthful to get your head around, in any case to get your lips around, let alone your, your, mental concepts around" (P1009:p76).

This difference in the language used by medical staff was highlighted when one participant referred to the language of the doctors, 'they', as being different to her own 'that's what they say isn't it, tumour' (1005:p450).

Even when the same language was used it was not always clear to the participant what was actually intended, for example:

'coz they say don't bend down and I thought, what do you call bending down?' (1005:p416) or just plain impractical, such as, when women are advised not to lift a kettle following hysterectomy, one participant added, 'you know, like the kettle. That is being crazy' (1014:p125).

Participants did talk about other sources of information such as friends and family, especially those involved in healthcare. The internet was mentioned as a good source of information but also as an unreliable or confusing source, especially when one is vulnerable following a cancer diagnosis, for example:

'you know, you can do and you can get a lot of information, then your head can be feeling all jumbled with a lot of information and you can feel a bit confused really' (1013:p127).

Written information for some participants acted as something tangible to refer to and represent their experience, or aspects of their experience, that needed confirmation, for example:

'but I do keep getting that letter out now and again and reading it where it says, you know, all clear' (P1005:p273).
This could then be discarded when the participant was ready to move on and leave the experience behind her, for example:

'I had all the papers but I threw them away the other day' (P1007:p261).

The participants described a range of needs for information and there were comments that suggested information could be empowering as well as frightening, for example:

'I just couldn't read the books because I lost my Mum from cancer, lung cancer' (P1014:p36) and ‘but I didn’t feel I had enough information and I didn’t know who to ask or where to go to get it’ (P1009:p213) and as one participant said when she had been told she had to come back to clinic urgently without being told why ‘I felt I wasn’t in control of anything for those 36 hours’ (P1003:p44).

This sense of the power of information was also reflected in the power the medical staff have because of their control of information and knowledge, which will be discussed in the theme transfer of responsibility to the surgeon.

7.3.2 Sub-theme: Preconceptions

The participants in this study described attitudes towards open and laparoscopic surgery which were based on their preconceived ideas or notions of the surgery. These preconceived ideas often mirrored the concerns expressed in the medical literature (see Chapter 3), relating to complications, such as infections, and quality of life issues, such as mobility, pain and length of stay in hospital.

There was a sense that the participants viewed open hysterectomy as a 'big operation' which would require a large incision leaving the patient bed ridden. The
descriptions of open surgery could be graphic and express a sense of violence, for example:

‘this great big scar’ ‘you know, cut right across my abdomen’ (1003:s124) and in relation to another patient on the ward ‘the terrible trauma of, of being, her body sliced open in two directions’ (1009:p281) and ‘i think she would have been quite bed bound really’ ( P1008:p279).

As these ideas became apparent during the interview, I explored where some of these notions had originated. I asked the participants if they knew other women who had been through a hysterectomy but very few did, certainly not anyone with whom they had a close relationship. During the interview some women acknowledged that what they described was a perception, rather than coming from any evidence or experience, for example:

‘I would have a larger wound and the healing would take longer (R: yeah) um, and I think er, would it have been more painful postoperatively?......I would imagine’ (1013:p242) and in relation to laparoscopic surgery ‘presumably a, an easier recovery time, a less sort of dramatic um, you know, operation altogether. I don’t really know because I’m afraid I know very little about that kind of surgery’ (P1003:p333).

The participants described their perception of laparoscopic surgery compared to open hysterectomy, such as:

‘you’re on your feet quicker...cuts down the risk of infection’ (P1004:p159).
Because open surgery was seen as a bigger operation with more potential side effects the participants viewed laparoscopic surgery as 'obviously' better, for example:

'but obviously it would be better to do it that way rather than having a big cut across the pelvis' (P1011:p75) and 'why would anyone want to have something that hurts when they can have something that doesn't?' (P1011:p790).

One participant described laparoscopic surgery as something which was different to surgery when she described being given a choice of an operation or keyhole:

'Instead of having the operation you can have, like, keyhole or something else' (P1014:p50).

None of the participants had experienced cancer personally before the diagnosis of endometrial cancer and only one participant had undergone abdominal or pelvic surgery before, having both her children delivered by caesarian section. One participant did comment on the potential benefit to society of her being out of hospital sooner and freeing up a hospital bed.

Other comments in this sub-theme were around participants developing ideas about what was happening by trying to pick up cues or clues from the behaviour or comments of the staff, rather than the information they were given or asking the questions. For example, one participant described saying to a friend:

'it can't be that bad or they wouldn't have cancelled...maybe I hadn't got a bloody chance' (P1005:p475).

7.3.3 Sub-theme: Relationships
The participants in this study all made reference to other people such as friends and family, the nursing and medical staff, other patients, colleagues and employers, the church, as being involved and having a significant influence on their experience. The local community offered support for some of the women but others had very little contact with neighbours.

There were references throughout the protocols to the intimate nature of the illness and procedure and there were some expressions of the need for female support. For example, when a participant’s son wanted to be more involved she declined saying, ‘it’s a women’s thing and that’s it’ (P*;p717). Another participant wished there had been a woman in the consultation with the male doctor and later added that she felt a counselling group might have helped:

‘there’s no woman sitting there saying look; you know, this really isn’t as major as it seems’ and ‘so I’d have thought a counselling group, certainly for people like me’ (P1009;p81;p371)

There was also mention of support offered by the nursing staff and most of the participants had met a specialist nurse. Some women managed to develop relationships with the nurses and other patients on the ward but most felt that the short hospital stay did not facilitate this, for example:

‘we, we did actually chat, you know, get to know one another’ (P1006;p221 referring to another patient on the ward and ‘obviously if you are only on that ward for one night you don’t get the same rapport’ (P1002;p474 referring to the nurses).

Participants also referred to their role in other people’s lives and in the support of friends and family, for example:
"friends I rang up and told, there was just this dead silence on the other end of the phone" (P1006:p409) and 'My sister cried when she heard that it was cancer. I said don't cry' (P1004:p101) and 'my daughter was shocked...childlike' (P1002:p40).

Several of the participants had dependent children, or grandchildren for whom they provided childcare.

7.3.4 Summary of Theme: Information and Support

Having laparoscopic surgery for endometrial cancer occurred in the context of the participants' individual lives. This was reflected in their understanding of the cancer and the treatment before, during and after the experience of laparoscopic surgery. Prior knowledge was described as low and it was information about what would happen and common understanding that was most lacking. Information was primarily obtained from the medical staff and this was expressed by the participants as they mirrored the information found in the medical literature. Information was considered to be both empowering and disempowering dependent upon access and understanding. Relationships with family, friends, work colleagues and social communities such as the church, provided a valuable source of information and support but the participants also described their role in the support of others. A description of the formulated meanings and sub-themes for the theme information and support are displayed in Appendix 7.

7.4 Theme: Independence

Independence developed as a theme in relation to the ways in which participants were stripped of, maintained or re-established their independence throughout the experience. This was both physical and psychological and was closely related to the theme of transfer of responsibility to the surgeon but was considered distinct from it because it encompassed aspects of independence not linked to the surgeon.
Independence incorporated the sub-themes of dependence and self-reliance and was expressed in 144 of the 699 significant statements and across 43 of the 185 formulated meanings.

7.4.1 Sub-theme: Dependence

Dependence concerned being dependent upon services and other people. It involved aspects of care or support on which the participants were dependent upon receiving. Having an illness often requires some level of dependence on others and the participants recognised this need and were fearful of it, especially those living alone, for example:

'all I was worried about, being on my own and not being able to cope (R: yeah) because I've always sort of done my own thing all my life and I don't want to have to.... I would rather they give me something' (P1012:p518).

The participants in this study demonstrated some of the risk factors associated with endometrial cancer as discussed in Chapter 2 and Chapter 6. These women were more dependent upon healthcare services as part of their treatment, such as having intensive care beds arranged or requiring diabetic control during the period of fasting for and after surgery.

The sutures used for the port site incisions were dissolvable but several participants needed to have these trimmed, often expressed as 'being removed'. This is not uncommon with dissolvable sutures when the ends irritate the skin or catch on clothing etc. Some participants were unable to access this service in the community and depended upon returning to the hospital. For one participant the laparoscopic surgeon 'removed' the sutures when she went to clinic for her histopathology results. Another participant commented on trying, while she was still
in hospital, to organise with her GP surgery for ‘removal’ of her sutures but the surgery nurses refused:

‘they told me to go to my GP and I rung up from (the hospital) before I left (the hospital) on the Friday, one of the nurses spoke to me, they wouldn’t do it’ (P1005:p156).

The participants were mostly positive about going home but some expressed having concerns about being able to cope, especially those who lived alone. Three participants went to stay with family following discharge from hospital. Two participants commented that they had been discharged ‘a bit too soon’, as one participant explained:

‘I was a bit wary about being at home on my own’ ‘I think on your own you would be better off with another day’ (P1012:s610).

Two participants were dependent on emergency medical advice following discharge, one from the GP and the other from casualty. There was also a sense of being dependent on the system and the services offered or required and not having any choice. For example, one participant commented on the embarrassment of the intimate examinations and another on a preference for a female doctor despite not having access to one once referred to the laparoscopic surgeon:

‘Everybody looking and talking to you and you feel embarrassed as well’ ‘I don’t want to see anyone’s face’ (P1008:s389) and ‘I liked having a, er, a woman, um, consultant’ (P1009:p26).

Being lucky or being fortunate was referred to specifically by 10 of the participants and this was often repeated during the interview. Luck seemed to be
something that was independent of all other aspects of the experience and conveyed a lack of control, a level of dependence on something other than oneself.

Dependence upon nursing care was also described and was primarily delivered by the specialist nurses, the ward nurses and the recovery nurses. I had not labeled this a nursing study and had referred to myself as a researcher in all written information but during the analysis I became aware of being asked health-related questions and being directly referred to as a nurse. This may have had an impact on the amount of dialogue concerning nursing care but it did not inhibit the participants from expressing a range of issues incorporating what they perceived to be good nursing care and poor nursing care.

Dependence upon nurses was described primarily during the time in recovery and in the first 12 hours postoperatively. Very specific comments about poor nursing care tended to come from one cancer centre and often related to specific nurses or groups of nurses, such as agency or night nurses. Poor nursing was associated with a lack of 'caring' or 'nurturing', although one participant did comment on the effect of the low number of nurses per patient:

'but then there was one, two nurses on, um, to see to all the, all the women, one, one night, so they won't do anything, you know, how could they, they didn't have the time. They had patients calling them' (1004:p163).

However, NHS nurses were described as more knowledgeable but fewer in numbers than those in the Private Sector and 'older' nurses were mentioned as being more understanding:

'I don't think the level of nursing understanding is always quite the same at somewhere like (private hospital) as it is at (NHS hospital). You, on the other hand,
get more of it' (1001:p70?) and 'I had, I had older nurses (R: um) there were a
couple of youngsters, but the older nurses were more understanding' (P1004:p168).

One participant was particularly concerned to come in contact with a male nurse
in recovery when she woke to find a:

'man lifting up the bedclothes and the pad to see how much I was bleeding (R:
um) I think that's wrong, totally wrong. (P1004:p232).

Positive comments about nursing care primarily concentrated on the nurses
being 'kind' and 'nice'. Most of the participants had made contact with the specialist
nurse(s) although there was a clear difference between the two centres in the level
of contact and reliance on the specialist nurse(s). Several participants were
dependent upon nursing advice following discharge from hospital and were not
always able to get help. One participant described the discharge information which
suggested ringing the ward for advice if required but this proved unhelpful:

'but then they give you that (ward number), so you could ring the staff, and when
I ring there, she say "oh we can't help you just go to Casualty"' (P1002:p567).

Being dependent was also expressed as being vulnerable and 'being done to'
rather than being an equal partner. This concept was also seen in relation to the
surgeon and is discussed separately in the theme transfer of responsibility to the
surgeon. Participants gave accounts of 'they' doing what was required, or what
'they' wanted to do, sometimes without the participant even being aware, despite the
fact it was being done to them, for example:

'I woke up with a catheter, an IV and I think they gave me pain relief
intravenously in the first, I don't know' (P1012:p33) and 'it was that oxygen, they
made me have loads of that, and it was that that made me feel sick' (P1005:p116) and 'because I wasn't part of it, being unconscious' (P1009:p223).

This was also expressed as being on a conveyor belt and not being treated as a person or an individual, such as:

'I did feel as though I was on a conveyor belt' (P1006:p211) and 'I mean we're just another, another, another person aren't we to them really' (P1005:p731) and 'I feel everything is very much pigeon-holed, it's all age-related...everybody's so different' (P1009:p604).

One participant did go on to comment about one particular member of staff who made her feel differently:

'first time that I felt really that anyone had actually cared about me as a person, actually fitted in with what I needed' (P1009:p172).

Participants made direct reference to feeling vulnerable or isolated at times of most dependence, such as when treatments were decided or in the immediate postoperative period. For example, one participant described being initially refused treatment and the way that was communicated to her and her powerlessness to influence the decision:

'you're very vulnerable when things like that go on and you don't need any abuse' (P*:p66).

7.4.2 Sub-theme: Self-reliance

Self-reliance was expressed by the participants in connection with being able to take care of oneself and not being dependent upon others. This included being self-reliant in hospital and at home following discharge, for example:
'because I didn't need seeing to...I was sort of left to my own devices and happy
to be so' (P1003:p710) and 'I wouldn't have been able to do anything like hoovering
or cleaning or anything like that but I was able to get up and get dressed and sort of
get food really but that was all I needed to do' (1011:p103).

Mobility was described as a key factor in maintaining independence. Participants
described being mobile after the operation, most were out of bed the next day and
'sort of toddling along' (P1003:157). Although, some participants described trying to
be mobile or being encouraged to be mobile, before the drip and catheter were
removed, this could prove difficult, for example:

'when you are hooked up with all these things it is so difficult' (P1002:p290) and
'once that was taken out the next morning I was away' (P1012:p196).

There was also a sense that this aspect of care was not well coordinated with
some of the participants being asked to mobilise with the drip and catheter only
minutes before the doctors instructed their removal.

The participants also described how mobile they were in relation to other
patients who had not had laparoscopic surgery, for example:

'she was walking really bent low, yeah, I was walking all right really'
(1005:p366).

For a few of the participants that fact that they could manage to walk up and
down the stairs relatively easily was important for being able to go home and
manage independently.
Going home was associated with having the freedom to do as one pleased. One participant, who had struggled to get a cup of hot water to drink in the hospital, said that although she went home 'a wee bit too soon' she added:

'...and again, I wanted to come home even just to have a cup of water' (P1002:p135).

This sentiment was also expressed in relation to staying with friends or family where the participant would need to adapt to lifestyle of their host, for example:

'just get up and have it as I wanted...if you’re with other people you have to eat at their meal times and things' (P1006:p202).

Being self-reliant and not inconveniencing others was also expressed by the participants in relation to hospital visiting and support at home, for example:

'my friends are working and I think well if I'm walking around all right I don't want to bother (them)' (P1010:p329) and 'you feel you’re imposing, I don't want to have to depend on them' (P1012:s611) and 'I wasn't going to ruin other people's Easters' (P1006:p145).

Participants who were used to living alone prepared in advance for their discharge from hospital and potential dependence by filling the freezer, sorting out animals, arranging for shopping to be delivered etc. This was seen as a way to maintain self-reliance and minimise inconvenience to others. One participant commented on having dissolvable sutures which meant that she did not require access to healthcare services for them to be removed, adding to her independence. There were also expressions of being actively involved in the recovery such as:
‘I was swimming a lot, because it’s the best recuperative thing you could ever do’ (P1009:p367) and ‘I broke myself into it’ (P1005:p384).

Self-reliance also included expressions of individuality and taking control of the situation, for example:

‘you’ve got to handle it the best way for yourself, don’t you?’ (P1006:p417).

Taking some control also included instances when the participants refused treatment or questioned what was being said by the medical team. One participant had been told that her uterus was too big to be removed laparoscopically and she responded with:

‘the womb didn’t look terribly big to me’ ‘I would really like you to go back and look at my scans again and tell me what size my uterus is’ ‘because I don’t believe it won’t come out vaginally’ (P1009:s431). Her laparoscopic surgery was successfully completed.

It was, however, acknowledged that questioning the medical team could be difficult, for example:

‘I upset her because I said: do you know my history?’ (P1006:p447) but the participant went on to add ‘but I wasn’t going to give in...sometimes you just have to make a stand’ (P1006:p456).

Participants also described the difficulty experienced when telling other people about the cancer and the surgery but this also involved making decisions about who to tell and who not to tell. I had not anticipated that so many of the women would be reluctant to talk about the cancer with close family members or the surgery with friends and colleagues, for example:
'I won't tell my husband' 'I certainly don't want my husband and my, you know, son and daughters to be worrying about it' (P*:s459) and 'I never sort of spoke like that to my husband so I'm sure I'm not going to talk to the kids like that, am I?' (P1005:p262) and 'I didn't tell my mother, I still haven't told my mother' (P1011:p164).

The reasons given were primarily to protect others because they were elderly or had lost someone to cancer, or to maintain a level of privacy, sometimes linked to an embarrassment of the subject:

'it's just not a thing, well I think, that a mum discusses with her sons' (P1005:620).

7.4.3 Summary of Theme: Independence

Independence related to the ways in which participants became dependent upon others and the way in which they maintained or regained their independence both physically and psychologically. Feelings of vulnerability were expressed in the interviews, as was a sense of being reliant on others, especially around the time of least control, such as diagnosis and immediately after the operation. Nurses provided care when the participants were at their most vulnerable and dependent. Examples of what was perceived as good nursing care and poor nursing care were given but the most important attributes of the nurses were described as kindness and niceness. However, the participants also described areas of the experience where they were able to take control, as well as being able to maintain a significant amount of independence with a low level of reliance upon others because they were able to care for themselves and were relatively mobile. A description of the formulated meanings and sub-themes for the theme independence are displayed in Appendix 8.
7.5 Theme: Normality

Normality was identified as a theme which encompassed a sense of what was normal or usual for the individual participant and what this meant before diagnosis, during treatment and after treatment had finished. Normality was expressed as how things appeared to be and the participants' perceptions of how normal life was interrupted and altered. Normality was expressed in 189 of the 699 significant statements and across 43 of the 185 formulated meanings. The sub-themes identified as representing this theme were, appearance, being changed and disruption.

7.5.1 Sub-theme: Appearance

Appearance was concerned with issues relating to what could be seen and how things appeared to be, or not to be. This was both physically and psychologically. The endometrial cancer itself could not be seen or felt by the participants and, even when there had been a sense of knowing that something was wrong, the participants described not being aware of, or in control of, what was happening in their body before or after the diagnosis, for example:

‘flippin glad that I went because you don’t know, you just, you, you don’t know that you’re ill do you?’ (P1005:p80) and ‘if it is still there, I don’t know’ (P1008:p247).

The sense that the participants no longer had an understanding of their body was also expressed in relation to not having much to show for having had the surgery, little evidence that something significant had taken place inside them. This could lead to a sense of disbelief, for example:

‘that’s it but and you’ve got nothing afterwards, nothing to, no stitching or no, all there is, is, like the, two, two little holes and like a line, that’s all you’ve got’
(P1005:p109) and 'you've got it in writing as well, I kept looking at it and thinking, no, this wasn't me was it?' (P1005:p183) and 'you know I kept thinking have I dreamt it, or what, did they take...sometimes I haven't got a clue' (P1014:p241).

Because of this lack of outward signs of having had cancer and surgery, a sense of disbelief was expressed by other people:

'She said: I cannot believe that you have just had a major op...(a friend had said that the participant) couldn't have had that because my daughter was flat on her back and (so) she couldn't have had a proper hysterectomy and I said: I'll bring the letter to show them, if they want, yeah' (P1010:632).

However, for some participants even the small scars were a permanent reminder of the cancer and the surgery, for example:

'unless I look in the mirror and, you know, I see it, I think oh God, you know, cover it up and remind me about it again in a few months when it's time to go (to clinic)' (P1005:p243).

Three of the participants made direct reference to the cosmetic appearance of the laparoscopic incision scars, suggesting that scarring was unimportant for older women:

'not that it matters at my age' (P1006:p500) and 'I don't think at my age I am going to worry about it' (P1001:p340).

When discussing her preference for laparoscopic surgery, one participant wanted to make it clear that it was 'not for the vanity aspect' (P1003:p666).
The participants also expressed concerns about not wanting to appear ill and be seen 'looking at my worst' (P1003:p535). This keeping up of appearances was also expressed in relation to being required to remove false teeth before the operation, especially when being spoken to by the medical staff, for example:

'he was really nice...and I thought oh God, he's going to see me in a minute without my teeth' (P1005:p317).

Not obviously appearing ill meant that the participants had more control over who to tell about the cancer and/or surgery as discussed in independence. However, the participants also commented on how well they looked and the disparity with how well they actually felt, for example:

'when they look at my face they say “you look OK” and I say “yes” but only I know the pain, the discomfort' (P1008:p672).

7.5.2 Sub-theme: Being Changed

Participants in the study described being permanently altered or made different by the experience both physically and psychologically. This alteration of the physical self also had the potential to impact psychologically, for example:

'and I’ve now got bits missing that I came in here with, they’ve gone’ ‘take away the so important bits from me’ (P1009:s504) which resulted in ‘certainly I can’t feel quite so much in, in orgasm, not yet, maybe it’ll come back, I don’t know, maybe it’s all psychological, who knows, but it’s not it’s not quite the same’ (P1009:p884).

Other less significant changes were commented on, such as:
'I kept off the fizzy drinks coz I didn't ea..., can't remember if (surgeon name) told me before that or after to keep off fizzy drinks, I think it might have been after, it was her that told me about fizzy drinks and I never have them now' (P1009:p313).

This sense of being different created a degree of difficulty with telling other people; others would somehow be aware that the participant was now different, for example:

'but we've not told them the reason why, because I think sometimes you, you kind of...sometimes if you say it's a cancer, then everybody's looking at you differently' (1008:p315)

For the participant who had a preinvasive lesion on final pathology review, there were also expressions of regret at having lost her uterus, primarily in relation to losing the cervix:

'obviously represents something of your sort of womanhood' 'and I regard having all my internal organs out, that are to do with me as a woman, a major body re.., and soul and psychological, reconstruction' (P*:s419).

This was not identified by any of the other participants and this participant did go on to add that she probably would not feel the same if the pathology had confirmed an invasive cancer as anticipated.

One of the participants who was premenopausal at the time of surgery was pleased to find that she did not have any menopausal symptoms and one participant described the laparoscopic surgery as having incidentally improved her preoperative bladder symptoms.

7.5.3 Sub-theme: Disruption
Disruption was described as the way in which normal life was interrupted and re-established, even if that sense of normality was redefined or changed. For some participants having cancer led to a return to vaginal bleeding or very heavy vaginal bleeding which was seen as inconvenient or severe enough to require immediate medical attention, for example:

'I just couldn't even get up from my desk the bleeding was so heavy, um, and when I came home it continued to be heavy and I don't think I went to work the next day, or maybe I didn't have to' (P1013:p66) and 'But I was getting frightened with the bleeding' 'if it had happened to me down the middle of (town) I'd have had to walk home covered with blood' (P011:s522) and 'I thought, oh, my stomach...and that evening I sat in that chair and all of a sudden I got this warm feeling and all this brown, dark brown stuff came running down... blood came out, so we went to the hospital' (P1007:p9).

The level of disruption experienced by postmenopausal women who have become used to not having periods, or the potential to be seen to bleed in public, together with a recognition of bleeding as abnormal maybe what takes women with postmenopausal bleeding or heavy bleeding to see their doctor and why endometrial cancer is more readily diagnosed in the early stages of the disease, as discussed in Chapter 2.

The only other pre-diagnostic symptoms discussed were tiredness and a poor appetite. However, these were only described by two participants and may reflect the early stage of disease for this group of women. Several participants also described the disruption to normal life associated with the anxiety and fear of cancer, as discussed in the theme having cancer. For example, one participant
described waiting for her first outpatient appointment with the gynaecological oncology team:

'I couldn't sleep, I was, it was on my mind 24/7' (P1005:p249).

Being admitted to hospital not only removed the participants from their normal environment, it also affected normal bodily functioning and participants described difficulties with constipation, nausea, eating and drinking, taking HRT, having a catheter, etc. Disruption was also seen to normal values, the way an individual would choose to live, such as the effect an illness or hospital admission would have on an individual who ordinarily 'doesn't take tablets' (P1012:p449).

Constipation was described by several participants. It occurred in the hospital and was perceived to be as a result of analgesia or eating the hospital food and continued at home. Eating and drinking was disrupted as part of the preoperative work up and also postoperatively. Most participants were able to eat again the day after the operation but some remained without food for longer, for example:

'I ate and drink nothing that first day after the operation' (P1014:p45) and 'but when I tried to eat I got nauseous... breakfast, um, I did manage to get it down but lunch was difficult' (P1005:p91).

Disruption continued after discharge from hospital with advice not to drive, being told not to work, not to have sex and not to take HRT until the final histopathology was reported. To add to the difficulty for one participant, she was told not to drive or use public transport but asked to attend the out-patient clinic a week following discharge. She had to get a taxi.
Of the seven participants in paid employment; some expressed the sentiment described in the literature review where they wanted to take their entitled amount of time off regardless of how well they felt, some described the difficulties of going back to work full time and one participant continued to work from home virtually on discharge from hospital. Some participants even described being well enough to enjoy the time off work:

'and I didn't, didn't sit about and it was quite nice I think it was May, and I was walking up and down the garden...my (name) come round and we'd go shopping' (P1005:p138)

Several participants did, however, comment on feeling tired, for example:

'all of a sudden it sort of comes over you, you know, you got to sit down and it's an effort to get up' (P1005:p376).

But one participant who had been expecting to feel tired was delighted when she did not:

'I was sitting there reading, had my radio and thought well I'm happy, not the slightest bit tired, and I just couldn't believe how I never, um, I just never felt tired. (P1010:p528).

The postoperative complications reported by the participants were minor wound infections and urinary tract infections but there were also two reports of significant back pain following surgery and one participant went on to develop chronic back pain. Postoperative pain was primarily expressed as discomfort which required what the participants viewed as very little in the way of analgesia, for example:
'sore and uncomfortable to a certain extent' wouldn't say it was painful' 'it was uncomfortable' (P1001:s7) and 'I wouldn't say you were, discomfort but not pain' (P1011:p577) and 'I took my painkillers that night and Sunday night, Sunday and I thought, I, I was pretty sure I didn't need them' (P1006:p96).

This discomfort did cause some disruption to normal life for some of the participants:

'I am finding even now some slight discomfort in my, in my shoulders and my back' (P1003:p198) and 'I do get an aching in my abdomen if I've been, you know how it is when you're doing housework and you're bending and you're doing things' (P1013:p183).

Several of the participants commented on the perception that laparoscopic surgery was less painful then open surgery. One participant was pleased to be informed by the surgeon before the operation that laparoscopic surgery would be less painful because she had:

'got enough pain to cope with without having all that as well' (P1004:p84).

Getting back to normality was seen as important and there was a general sense of being able to get back to normal relatively quickly, for example:

'they said I should take it easy for a bit but I just kept walking round and sitting down for a bit...I felt all right actually' (1005:p134) and 'they said it would be quicker but I didn't think it would be that quick' (1012:s112).

However, the participants also described having to take it easy and restrict activity, for example:
'because I don't feel I am still terribly fast when I'm walking' 'this need to take things easy' 'still an awful lot you have to be careful with' (P1003:s116).

The diagnosis of cancer created the first significant adjustment to normality and the admission to hospital created the second. Not being able to eat in hospital was commented on both in terms of fasting before and immediately after the procedure but also because of the poor quality of the food, for example:

“didn’t eat very much because the hospital food’s not all that good” (p1007:p358).

Several participants described food being brought in by their visitors. Participants also had disturbed sleep in hospital because of other patients or the monitoring required postoperatively, for example:

‘pretty tired because the night before the two other patients had been being sick’ (P1003:p163) and ‘I didn’t sleep that night, that machine by your, by your head going: flick whirrr, flick, flick, whirrr, flick’ (P1006:p83) and ‘I can’t bear being on wards with other people, especially when you don’t (usually) have anybody around you sleeping and snoring and, and creating’ (P1004:p358).

Some of the patients had single rooms and there was a mixed reaction with some pleased to be in their own room and others who did not want to be on their own. Both hospitals had dedicated gynaecology wards and so mixed sex areas was not an issue.

A general fear of hospitals was also expressed, as was a fear of the risks associated with hospital acquired infections, for example:
'but you won't be in there for that long and then, you know, won't get any MRSA, it's rife innit' (P1005:p99) and 'well, the superbugs (R: yeah) because we all know what can happen there' (P1007:p177), one participant even discouraged her grandchildren visiting 'I didn't let them come in...so much infection all around' (P1002:p433).

There was also a sense that being in hospital represented a loss of freedom, being in prison, which was highlighted in the language used to describe being discharged: 'I got out on the Sunday' (P1011:p121) and 'they wouldn't have let me out otherwise' (P1014:344).

7.5.4 Summary of Theme: Normality

Normality represented the way in which the normal lives of the participants were interrupted. Having laparoscopic surgery for endometrial cancer affected the participants’ sense of what was normal physically, psychologically and socially. Having symptoms, the discovery of being ill and having surgery changed how the participants viewed themselves and how they felt they were potentially viewed by others but not having any outward signs meant that the participants had some control on how much to disclose to others about their illness and surgery. Having symptoms and being admitted to hospital for surgery caused a significant disruption to normal life and bodily functions. The relatively low levels of pain associated with the procedure minimised the disruption but taking time off work was a personal decision based on beliefs and type of work. A description of the formulated meanings and sub-themes for the theme normality are displayed in Appendix 9.

7.6 Theme: Transfer of Responsibility to the Surgeon

The figure of the surgeon was a significant feature in all of the protocols. The experience of the cancer and the surgery was fundamentally linked to the surgeon
and resulted in the sense of a formal handing over of self-responsibility to the care of the surgical service but primarily to the individual surgeon. This transfer of responsibility to the surgeon was expressed in the sub-themes faith in the surgeon, modern and the passive patient and was seen in 157 of the 699 significant statements and across 32 of the 185 formulated meanings.

7.6.1 Sub-theme: Faith in the Surgeon

Faith in the surgeon was described as a belief in the ability of the surgeon to perform the operation and cure the cancer. This was present whether the participant had actually experienced much direct contact with the surgeon or not and was linked to a perception that the surgeon was an expert in his field, even the expert. This was reinforced when some participants looked up the surgeon on the internet or because the participant had been referred to that surgeon specifically because of his knowledge and expertise. This was also seen with surgeon to surgeon referral, where the initial surgeon did not possess the required expertise. For example:

'my husband Googled (named surgeon), being in the top 200 surgeons' (P1003:p580) or, when a participant asked the Initial surgeon why her care was being transferred 'because he does keyhole..."will you do it?" he said "no I don't do that" he said "(named surgeon) does that" (P1010:p436) And a combination '(named surgeon) as he's the best laparoscopic surgeon anyway in the country' 'we had the best surgeon', the referring surgeon 'said (named surgeon) was the best surgeon and he does it laparoscopically' 'and he's very nice and he's doing all the laparoscopic cases' (P1008:s371).

The laparoscopic surgeons were seen as being superior to other doctors and surgeons who had failed to diagnose the cancer or who had been unable to provide treatment:
'(referring surgeon) thought that it was a polyp, sort of polyp and it was (named surgeon) that found that it wasn't' 'he diagnosed that it was sinister' (P1001:s3) and '(referring surgeon) was really against it, he said: no way!' (P1012:158).

This recognition of expertise formed part of the faith in the surgeon that was also directly expressed by participants, for example:

'I had so much faith in him' 'he would do the right thing' 'he would do the best possible' (P1001:s4) and 'I...I mean I...I just trusted him' (P1006:p399).

Faith in the surgeon was also expressed using religious terminology, for example:

'it's a blessing when it's (name surgeon)' (P1002:p411) and 'but thank God for (named surgeon)' 'Thank God, and, and (named surgeon)' (P1012:s602).

There was a sense that surgeon embodied the procedure and the success of the procedure. One participant, in the validation interview, clarified my interpretation of her faith in the surgeon by saying 'he saved my life' (P1001:s1), while another participant 'could have kissed him' (P1002:p412). The successful outcome reinforced the appropriateness of the decision to transfer responsibility to the surgeon.

Faith in the surgeon and his expertise was expressed by most of the participants and appeared early in the interview process. At one of the first interviews, the participant had been initially seen in the private sector and had prolonged personal contact with the surgeon. I considered whether her faith in the surgeon was linked to the level of contact she had as a private patient and so, as other participants expressed this theme I asked directly about their degree of contact with the surgeon.
However, most participants described very little contact with the surgeon preoperatively and one of the surgeons met several of his patients for the first time as they waited for the procedure in the anaesthetic room. One participant only met the surgeon several weeks after the operation. For example:

'I only saw him I think twice' (P1002:p417) and 'I never even met (named surgeon) until, they were trying to knock me out in the theatre part' (P1010:p349) and 'which was the first time I saw him ever, was after my operation, I never saw the man who was going to operate on my body, I never saw him before he did it' this participant went on to add 'which again I didn't like as a principle, but I was happy that he had agreed to sort of you know, shove me into the list very quickly at the last minute' (P1009:p196).

When I asked one participant if she had met the operating surgeon before the surgery, she initially thought she had but then went on to reflect more accurately:

R: and so did you meet him before the operation? P: yeah...uh, no, no I never, no only met him when I was going in to have the operation and, she (the referring surgeon) told me he would do my operation. (P1014:194).

Even when aspects of the surgical care had not gone according to plan, the participants felt blame lay away from the surgeon and/or the surgery. There was a sense that the surgeon 'could do no wrong' and this displacement was used as a mechanism to maintain the perception of the surgeon as expert and also justify having faith in him. For example, one participant describes a wound infection:

'oh yes, that, I don't blame the surgery for that, I blame the nurse for that because by pulling me up, that's when it started...that was nothing to do with the surgery it was just bad luck' (P1001:p128).
Another participant described significant pain but did not feel the laparoscopic surgery or the surgeon was at fault:

'when I was very sick, morphine every four or five hours, I wasn't eating for two weeks, she prepared to take me back to the hospital, and being that constipated... It's just one of those things, any surgery do have a bit of risk' (P1002:s56)

Another participant described her negative feelings about not meeting the surgeon sooner but went on to say: 'it wasn't his fault, it's my fault but, um,' (P1009:p797).

7.6.2 Sub-theme: Modern

Laparoscopic surgery was described as 'modern', 'advanced' and 'innovative' compared with the 'usual', 'traditional', 'old fashioned' open hysterectomy. There was an element of laparoscopic surgery being seen as something which represented the natural progression in medicine, for example:

'I suppose that's how things have progressed since then' (1005:p400) 'wonderful isn't it what they can do now' (P1007:p275) one participant described her GP's response as being amazed that 'you can do all that keyhole?' (P1006:p481).

This was seen as a positive moving forward in the way that medicine was considered to have improved over time. One of the hospitals was part of a relatively new building and this sense of being modern was also associated with this environment.

7.6.3 Sub-theme: The Passive Patient

Taking a passive role was discussed to by all of the participants. This passive role could be almost childlike with the surgeon or doctor in the role of parent. This
was expressed when participants did not admit to behaviour they felt the doctors would not approve of and even told ‘fibs’, for example:

‘I’d been spotting for two years, although I told them it was only a year,’ (P1004:p16).

The participants also expressed concern that they should be seen to be behaving, doing as they had been instructed to do, for example:

‘I did everything according to the, the pamphlet’ (P1001:p139) and ‘I didn’t Hoover and I didn’t do something else, something else heavy I didn’t do’ (P1010:p52) and ‘it was all right, I took it, they said I should take it easy for a bit, I just kept walking round and sitting down for a bit’ (P1005:132).

Not wanting to complain could also be seen as part of being passive or being good but has been discussed primarily in relation to independence. One participant commented on how difficult it was not to be passive and go against medical advice:

‘putting it off for 2 months, so guilty that I, you know, I might be doing something terrible to my family and leave them without a mother and should you be doing this just, just for work, God, what have I done here, I did it eventually, but it took so long (R: yeah) 2 months and I was made to feel very guilty for that 2 months delay and that gave me sleepless nights and I don’t, I wish I hadn’t had to put myself through that (R: um) really’ ‘at which he was quite sort of, raised his eyebrows and thought I was stupid and wrote down: she will, you know, she won’t do it straight away, she’ll consider it’ (P*:s476).

Participants also described being treated as a child and being vulnerable by being taken care of, as well as wanting to be taken care of:
'we've been looked after at every stage' (P1008:271) and 'and then she said you will be OK' (P1014:61) or, with regard to having to walk down to the operating theatre, 'why do they make you walk down there?' (P1005:284).

This role of the child being taken care of was also expressed by one participant who described enjoyment at being the centre of attention:

'I quite enjoyed it actually, it was, you know, people bringing me food in and pampering me (P1004:182).

This was reinforced with expressions of the surgeon and doctors being seen as different to the participants, belonging to an elite group that the participant was not a member of, for example:

'And of course if only doctors, you know how doctors are, if they suspect anything but they're not happy, or with the practice of a colleague, they wouldn't criticise, but usually they'll not criticise their colleagues at all do they?' (P1013:77) and 'I went to his clinic but I didn't see the man himself' (P1013:115).

Taking a passive role was made easier by seeing the surgeon / medical staff as different and as powerful, in control of the situation and information, 'all knowing', for example:

'Is it cancer? And he said: I don't know. I don't know, he said, and I was thinking you do know' (P1010:855) and 'and he said he know what I had, he didn't tell me, he wanted to make double sure' (P1014:13).

This was also described in relation to the laparoscopic surgeon being the only person with the knowledge and skills to know what was best and make the decision to do the operation laparoscopically, for example:
'it was his decision, he’s the surgeon, you know’ (P1003:p119) and ‘I think they probably decided what was best to do, they were going to do the surgery in what way they normally do it’ (P1011:p75).

This was reinforced during the surgical consent process where the participants were informed that laparoscopic surgery may not be possible and that only the surgeon could decide at the time of the operation, firmly placing control with the surgeon, for example:

‘either be laparoscopic or, depending on how easy or difficult it was, to try and do it laparoscopically’ (P1003:s94) and ‘he said he thought he could do it, if it was too difficult he’d have to do the other one’ (P1006:390).

This had the effect of making the surgery more desirable, something elusive and only available if ‘lucky’ for which the participants then became very grateful, for example:

‘he said there’s always a chance that you may not be able to have keyhole and that was, I thought, oh God, I hope I do have keyhole and then when I come round, they were all saying to me: oh, you’ve had keyhole surgery!’ (P1010:p240).

This sense that the surgeon was the only person who could decide on the surgery contributed to dependence on the surgeon and expressions of not feeling able to make decisions which included knowing if anything was wrong or whether the cancer had come back, for example:

‘I just wanted to trust them and you know, they, I felt that I could trust them and I didn’t want to look it up, so I just felt, just take it one step at a time and I was happy with what they explained to me’ (P1013:s657) and ‘if they said jump through a ring
of fire I would have done it' (P1010:p361) and about being monitored for recurrence, 'was reassured to find that I will be, sort of, kept an eye on for the next two years' (P1003:p252).

There were also descriptions of the participants choosing to be passive and the doctors being formally given the responsibility to take care of the participant, for example:

'because I thought they can worry about it, they're the doctors, they can do more worry and I sort of dismissed it, I'm not even worried about this I said, that's the doctor's problem not mine. That would be their worry not my worry' (P1010:s523) and 'I said I don't care what you do as long as you get it out,' (P1007:p53).

Because the surgeon and/or the doctors had been given the responsibility, the participants did not always want to know the details of the surgery. When I asked if the surgeon explained about the operation, one participant said:

'yeah I think he did, I think he did but I didn't really want to know much, I didn't really want to know much about it, I think it was enough, it was enough for me, it starts to get you more and more worried, the basics or whatever I think that, that is important but I don't want to know anything else' (P1011:s583).

7.6.4 Summary of Theme: Transfer of Responsibility to the Surgeon

The surgeon was perceived as a key figure in the experience of laparoscopic surgery in endometrial cancer. The surgeon was seen as the expert with the skills and knowledge to carry out the potentially curative procedure. Laparoscopic surgery was perceived as modern and advanced, making the laparoscopic surgeon more skilled than his peers. This level of knowledge and skill was seen by the participants as unattainable in this context, they described not even having control over what
was happening in their own body. The participants described faith in the surgeon and a formal transfer of responsibility for their care and wellbeing; trusting the surgeon with the knowledge and skills to act in their best interests. This occurred even if the participant had very little contact with the surgeon.

7.7 Summary of Findings: Phenomenological Description

The summary of the findings of the study represents what Colaizzi (1978) refers to as the fundamental structure or phenomenological description of the experience. This is the description of the experience developed from an understanding of the patients' perspective obtained through phenomenological inquiry. The fundamental structure of laparoscopic surgery in endometrial cancer obtained in this study can be described as:

Laparoscopic surgery in endometrial cancer involved acknowledging the presence of cancer and the fear and anxiety associated with the disease shaped all aspects of the experience. Trust was placed in the surgeon because of his knowledge and ability to perform the highly specialised procedure in which the individual patient could play no active role. Having cancer and having surgery removed the individual from the known and placed them in the unknown. The individuals brought with them prior knowledge and experience that was unique and situated in the context of their own lives but was unlikely to include knowledge of the complex world of cancer and highly specialised healthcare. This disruption of normality was both physical and psychological and a transition was made to the world of the ill, with loss of control, vulnerability and dependence on others. Flexibility and low levels of pain enabled the individuals to become independent rapidly after the operation and return to wellness, with few visible signs of being changed. A new normality and sense of self was achieved.
8.1 Introduction

This chapter presents a synthesis of the findings of the study and explores the themes in relation to existing knowledge. It forms the second part of the literature review, in keeping with phenomenological research, as discussed in Chapter 3. In this chapter, the phenomenological description of laparoscopic surgery in endometrial cancer was used to develop key findings in relation to the patient experience, nursing practice and healthcare services.

8.2 From Philosophy to Practical Application

Phenomenology originates in philosophy and was conceived as a research method by Husserl (1970) in an attempt to apply the rigour of traditional science to philosophical questions, as discussed in Chapter 4. However, its use in social inquiry and practice based disciplines such as education, clinical psychology and nursing, has been recognised (van Manen 1990). In nursing, the practical application of the phenomenological method was led by nurse researchers such as Benner (1994) and Munhall (2007) in North America.

In his critique of phenomenological nursing research, Michael Crotty (1996:7) argued that it is important for nurse researchers not to just describe 'what is' but to go further and describe 'what might be', thus taking the phenomenological description and considering its application into clinical practice. The phenomenological description of the experience of laparoscopic surgery in endometrial cancer produced in this study, was developed into a series of key findings, which can be used to improve services for women.
8.3 Key Findings

The key findings of this study have been summarised. For women in this study:

- The experience of laparoscopic surgery for endometrial cancer was overshadowed by the fear and anxiety associated with having cancer.
- Trust was placed in the surgeon to take responsibility for decision making because of fear of outcome, lack of knowledge and the recognition of the skills of the surgeon.
- Information needs were specific to the individual but primarily focused on being in an unfamiliar situation and environment with a need to be informed about what would be done, what to expect and the practicalities of coping, relative to personal circumstances. This information was sought from, but not always delivered by, healthcare professionals.
- Loss of control, vulnerability and dependence were associated with having endometrial cancer and laparoscopic surgery but the postoperative return to self-care and independence was rapid.
- Having endometrial cancer and laparoscopic surgery disrupted normal life both physically and psychologically but a functional level of activity was rapidly achieved following surgery, with little visible evidence that the surgery had taken place. Returning to normal activities, including employment, was variable and dependent upon individual beliefs and personal circumstances.

These key findings will be discussed in relation to the supporting literature and the underlying concepts of human experience that can be linked to the identified themes presented in Chapter 7. These concepts underpin the experience and overlap across the themes. The detail of the concepts will be presented in relation to where they were first described but are referred to throughout the discussion.
8.4 Surgery in the Shadow of Cancer

Although this study aimed to develop an understanding of the experience of laparoscopic surgery from women who had undergone the procedure for endometrial cancer, the participants described having cancer as a significant element of the overall surgical experience. The literature review, in Chapter 3, had identified a lack of research regarding the experience of laparoscopic hysterectomy from the patient perspective but given the significance of cancer in the surgical experience, the second phase of literature searching considered studies aimed at researching the experience of having surgery for cancer. This was also an area which appeared to be under-researched but several other interpretive studies also identified cancer as a significant feature of the surgical experience.

Bullen et al. (2009) identified the cancer journey as one of four themes representing the experience of having surgery for penile cancer. The nine men described their presentation, diagnosis, treatment and rehabilitation through the experience of having cancer and their identification of themselves as cancer patients. Worster and Holmes (2008; 2009) and Mizuno et al. (2007) set out to study the postoperative experience of colorectal cancer patients but discovered that participants chose to talk about their preoperative experiences because of the impact and burden of the cancer diagnosis and being constantly aware of having the disease. Being defined by cancer or being identified as a cancer patient, was described by Shaha and Cox (2003) as the omnipresence of cancer, in a phenomenological study of seven patients living with a diagnosis of colorectal cancer and as cancer patientness by Little et al. (1998), in a study exploring the narrative of 10 cancer patients.
In these studies, the significance of the cancer diagnosis was identified even for patients having surgery with curative intent and the overwhelming significance of cancer for the individual undergoing a surgical procedure was described by the researchers as an unexpected finding. In this current study, I had considered the potential difference between the experience of laparoscopic surgery for benign gynaecological disease and the experience for cancer, as discussed in Chapter 5. However, I too, had underestimated the impact that the cancer diagnosis would have on women who were likely to be cured with what amounts to relatively 'routine' surgery. The experience of laparoscopic surgery for the women in this study occurred through the lens of the cancer diagnosis and was the context in which the experience was lived. I had not explored this in my pre-study reflection and this finding was not identified in any of the research on laparoscopic hysterectomy for endometrial cancer. Neither was this seen in relation to open surgery for endometrial cancer and it may not just be applicable to the laparoscopic route.

Having identified the significance of the cancer diagnosis in this study and other studies where cancer was not anticipated to play such a pivotal role because of the curative nature of the disease, concepts of objective and subjective experience within phenomenology were explored. A key concept to emerge from phenomenological philosophy was that of bodily experience or embodiment which proposes that because human beings exist in a bodily form through which the world is received, the body is both subject and object (Merleau-Ponty 1962).

8.4.1 Embodiment

The concept of being embodied and experiencing the world through the body, emerged in the rise of phenomenology as a philosophical challenge to the dualism of Descartes mind and body divide. Embodiment concerns the lived experience of
our bodies and much of its origins are linked with the philosopher Maurice Merleau-Ponty (1962). Merleau-Ponty (1962) suggested that the body is more than physical object as described by Descartes and that consciousness is understood through the lived experience of the body; making the body and the self essentially one. Therefore, the spatiality of ones own body is made up of the psychological and physiological to become ones perception, or body image, consisting of the meanings by which it is recognised and understood.

In theories of embodiment, health is considered to be the state of unselfconscious being. This has been described as the body's disappearance from awareness or the absent body (Leder 1990). Disease establishes an unwanted consciousness of the body (Csordas 1994). This shatters the state of unselfconsciousness so that our understanding of ourselves as embodied no longer meets our perception, which disrupts our ability to negotiate the world (Benner 2000).

The women in this study described the process of becoming aware of the body and how the perception of themselves as having cancer deeply disrupted their sense of self, despite the likelihood of the disease being objectively removed. Descriptions of the overwhelming nature of the cancer diagnosis could represent a demonstration of the shattering of the state of unselfconsciousness and an example of the object / subject experience of lived illness for women in this study. The women also described being seen as object in the healthcare system and this will be discussed in relation to the surgeon.

The participants went on to describe their concerns about cancer in more detail and it was primarily the fear of cancer that encroached on all aspects of the experience from before the diagnosis, through the treatment, to living as a cancer
survivor. Powel and Clark (2005) used questionnaires to assess symptomatic
dysfunction following prostate cancer surgery but in an open-ended question, fear of
cancer was identified as a main theme in the qualitative analysis of the 25
substantive answers. This was a general fear of cancer, as well as a fear of dying,
which occurred at diagnosis, after treatment and if the disease recurred.

Fear of cancer appeared to affect how the participants approached healthcare
services, decision making and influenced satisfaction. To understand why cancer
should be so overwhelming as to disturb the sense of self, the literature on the
impact of cancer on the individual was reviewed; focusing on endometrial cancer,
gynaecological cancer and female cancers, taking into consideration the sub­
themes and narratives of the participants.

8.4.2 Fear
Cancer has been associated with death, dying and painful, mutilating treatment
for thousands of years: It was first described as a cause of death over 4500 years
ago and the early Egyptians were known to treat breast tumours with cautery (Lee
2000). Fanny Burney (2001), the novelist and playwright, vividly described the
torturing pain she endured having a mastectomy in the year 1811 without
anaesthesia because she was thought to have a breast cancer.

Fear of cancer continues into the 21st century and, according to Cancer
Research UK (CRUK) (2007 online), is our number one fear, ranking higher than
Alzheimer’s disease, heart attack and terrorism. Fear of cancer and cancer pain is
described by the general public (Toon 2007) and pervades the media in the West
with an increasing number of stories dedicated to all aspects of the disease (Clarke
& Everest 2006). CRUK was the top earning charity in 2005/06 with an estimated
£297m in voluntary donations from a public keen to ‘beat cancer’. This was over
£100m more than Oxfam in second place and Cancer Support MacMillan was also in the top 10 with an estimated £92m (Charities Aid Foundation 2007). Fear of cancer amongst the general public has also been associated with the potential to delay diagnosis rather than face the implications of having the disease, even though early diagnosis may affect outcome (Smith et al., 2005).

Fear of death, pain and painful treatments have also been identified in people who have been diagnosed with cancer (Kübler-Ross 1970; Levin et al. 1985; Penson et al. 2005; Roberts et al. 1997; Smith et al. 2005; Tobin & Begley 2008). Once diagnosed, individuals have been shown to be at greater risk of suicide, preferring to take their own lives than live with having cancer, cancer treatments and the possibility of a cancer death (Robinson et al., 2009). The level of fear identified in the literature was reflected in the fear associated with cancer described by the participants in this study. However, cancer and the fear associated with the disease, was reconceptualised by many of the participants on contact with healthcare professionals, primarily the surgeon. Cancer remained a life threatening disease but participants implied that their own cancer was different to cancer as they had previously understood it or as they perceived it was experienced by others. It was the subjective experience of the cancer that mattered not the objective reality of having the disease.

Several participants made reference to the embarrassment associated with pelvic examinations but only one described her fear of pelvic examinations affecting treatment, by leading to a delay in seeking medical help. Smith et al. (2005) demonstrated a correlation between having cancer in a more sensitive or sexual area and an increased sense of fear and embarrassment, which can lead to delays in diagnosis. Delayed diagnosis was not identified as a concern by most women in
this study, even though, over one third described having symptoms for longer than a year. This was possibly because they had early, operable endometrial cancer, as defined by the inclusion criteria. The only exception was the participant recommended to have adjuvant radiotherapy, who expressed concern that her General Practitioner had missed her diagnosis. This finding could represent an illustration of how outcome influences recall and/or interpretation of an experience because an experience is not a single event but, as van Manen (1990) suggested, a dynamic evolving process, always situated in context (Chapter 4).

The recognition of symptoms, or knowing that something was wrong, for many of the participants was the beginning of their story, sometimes described as the cancer journey or cancer pathway. Tobin and Begley (2008:34) also identified this sense of knowing and defined it as 'suspect-knowing-'knowing and yet not' and considered it to be an integral part of the cancer narrative. In keeping with phenomenological theories of embodiment, this was the time when the process of recognising the body signified the presence of illness and disruption of embodied self, when the general abstract fear of cancer became a personal reality. It was the time participants chose to describe as part of the surgical experience and was also identified phenomenologically by Wörster and Holmes (2008) and Bullen et al. (2009). In the process of recognising illness and seeking help from medical practitioners, the women entered the NHS rapid cancer referral and treatment pathway.

8.4.2.1 Rapid Treatment

The effects on the individual of the reconfiguration of cancer services discussed in Chapter 2 and in the Policy Review presented in Chapter 12, were described by participants in this study. Early diagnosis and access to rapid treatment have been tenets in the political debate in cancer since the Second World War and health
education of the general public has involved the central message that ‘early cancer is curable’ (Toon 2007). Although the messages are complex, the concepts of early diagnosis and rapid treatment are also well recognised in the media (Clarke & Everest 2006).

However, despite suggestions that rapid referral of patients with suspected cancer slows down the diagnostic pathway for patients where cancer is not suspected (Hanna et al. 2005), the psychological impact of the speed with which cancer patients are managed through the new pathways, has not been assessed. Beverly Hall (2003:57), a nurse, medical sociologist and cancer surivour, criticises ‘rushing the patient’ in the treatment of people with cancer because it does not allow individuals to acquaint themselves with the information needed to make rational decisions. Participants in this study identified an awareness of the rapid treatment because of the cancer diagnosis, which was described as reassuring but also had the potential to increase fear. This combination of reassurance and fear associated with rapid treatment has also been described by men having penile cancer surgery (Bullen et al. 2009).

For most participants in this study, further reassurance came after the uterus was removed and histology confirmed the early and, therefore, potentially curative nature of the disease. Despite this reassurance and reconceptualisation of the disease as something less significant than ‘real’ cancer, the fact that the cancer could possibly return was also acknowledged and living with this sense of uncertainty marked the cancer experience for women in this study.

8.4.3 Uncertainty

Uncertainty has been characterised as ‘a perception of being unable to assign probabilities for outcomes that prompts a discomforting, uneasy sensation’ (Penrod
2001:241). Cancer has been associated with the concept of uncertainty in illness, both as an acute and chronic condition. Mishel first described the *uncertainty in illness* model in 1988 and tested it with women who had gynaecological cancer (Mishel & Braden 1988). The four forms of uncertainty described by Mishel and Braden: ambiguity regarding the state of the illness, complexity regarding treatment, lack of information regarding the seriousness of the illness and unpredictability about the likely course of the disease, are applicable to a cancer diagnosis and were expressed by participants in this study. Shaha and Cox (2003) recognised the impact of uncertainty as part of the *omnipresence of cancer*.

Participants in this study expressed greater levels of fear and uncertainty at the time of diagnosis and on admission to hospital. Shaha *et al.* (2008), in a literature review of uncertainty in cancer (specifically breast, prostate and colorectal), considered uncertainty to be present from the outset of the diagnosis and the diagnosis was also identified as a time of uncertainty for women with gynaecological cancer (Mishel *et al.* 1984). In the literature on uncertainty and cancer, surgery was not identified as a specific time for increased uncertainty. However, surgery is primarily associated with the beginning of the cancer treatment pathway and the time of greatest hope and uncertainty regarding cure because surgical resection of a primary tumour that has not spread, still remains the most effective cure for most cancers and surgery is the point at which many cancers are staged (Department of Health (DH) 2007). In this study participants expressed uncertainty associated with the fear of cancer, the reality of having cancer and the potential outcome of the disease and this was also associated with a lack of control.
8.4.4 **Control**

Wellbeing has been linked to feelings of control, this may represent actual control or illusory control, what is important is the perception of control (Wallston 2007). An understanding of the concept of control, or the *locus of control*, was developed by the American Psychologist Julian Rotter (Shaha & Cox 2003). The locus of control concerns the extent to which individuals feel they can influence what causes good or bad things in life. The *internal locus of control* primarily comes from one's own behaviour and actions. The *external locus of control* is where powerful others, such as fate, chance or God determine events. Participants in this study made direct references to fate in the form of luck or fortune and God, as well as the 'powerful other' in the form of the surgeon. The *locus of control* is considered to be a continuum and all individuals are thought to be somewhere different along the continuum at different times and in different situations (Topping 2006).

Loss of control has been shown to manifest in many ways in cancer. Cancer is a disease characterised by the loss of control of normal cell function (National Cancer Institute (NCI) 2009a) which, as medicine has defined it, can only be diagnosed in a pathology laboratory. Women with endometrial cancer also have no control in the identification of the disease because the endometrium is only accessible to healthcare practitioners with specialist equipment and the extent of the disease is described after surgery has been completed. Participants in this study described uncontrolled vaginal bleeding affecting normal function, no control on treating the cancer because surgery was required and no control on whether the cancer would come back.

In their study of recovery following surgical treatment for colorectal cancer, Worster and Holmes (2009) described the loss and unpredictability of bodily
functions as deepening the perceived loss of control and certainty. For participants in this study, the recognition of the body as unreliable and uncontrolled was recognised and sustained with the uncertainty about whether the cancer would recur. The fear of cancer, uncertainty and loss of control were also associated with feelings of anxiety.

8.4.5 Anxiety

The anxiety associated with the cancer diagnosis identified in this study has been well described (Burgess et al. 2005; Edwards & Clarke 2004; Worster & Holmes 2009 online; Zabóra et al. 2001). Zabora et al. (2001) explored the prevalence of anxiety and distress in over 4000 cancer patients by cancer site. Gynaecological cancer was associated with the lowest rate of psychological distress at just under 30%. Cancers with an overall poorer prognosis and greater patient burden in the form of symptoms and treatment, were associated with the highest levels of distress (lung cancer being the highest at just over 43%). However, participants in this current study described the anxiety of having cancer being related to the concepts of having the disease rather than the site, symptoms or prognosis. This was also identified by Worster and Holmes (2009 online) and Bullen et al. (2009) in their phenomenological studies of the surgical experience and recognised by Madjar (1997) as the subjective experience of having cancer rather than the objectivity of cancer site, survival rates and expected recovery.

There was some evidence in the literature to suggest that women with cancer have higher rates of anxiety and emotional distress than men (Strong et al. 2007) but no gender difference was identified by Zabora et al. (2001). Higher rates of distress have been seen in women who have disease which is active (Strong et al. 2007) and those who have recently been diagnosed (Burgess et al. 2005; Norton et
indeed, the highest cancer suicide rates are seen at the time of diagnosis (Robinson *et al*. 2009). Although the patients were all under five years from diagnosis in the Zabora *et al*. (2007) study, no consideration was given as to whether the disease was currently active or at what stage the disease had been diagnosed.

For participants in this study, the fear and anxiety associated with cancer was more prevalent in the peri-diagnostic phase, when participants had active disease and were unaware of the stage and prognosis. According to Benner (2000), human experience is structured by temporality which includes a memory of what has past, engagement in the present and a projection of the embodied self into the future. Many of the participants were reassured once they had been given a diagnosis and treatment plan with a positive prognosis, enabling them to project themselves into the future. The participants also described a move away from uncertainty; from 'what could be', to, 'what would be'.

When reviewing the literature on anxiety in cancer patients, denial was seen as a mechanism by which uncertainty and anxiety could be managed. Denial was also a feature of the experience expressed by participants in this study.

### 8.4.6 Denial

In the literature, the denial expressed by participants in this study was a feature of a cancer diagnosis but there was a lack of consensus on the many different definitions (Vos & de Haes 2007). In psychoanalysis, Sigmund Freud introduced the concept of denial as a defense mechanism to cope with anxiety. He considered denial to be a dysfunctional form of disavowal of reality, replacing it with a more acceptable reality (Livneh 2009). However, in oncology practice, Salander and Windahl (1999) argued that, denial should be reconceptualised and that disavowal
of reality is something more than denial. They described denial as an appropriate coping mechanism covering the everyday experiences of cancer patients dealing with the strain of the diagnosis and disease. In the literature on illness and cancer, denial has been expressed as a continuum between the denial of clear facts and denial of ambiguous situations (Vos & de Haes 2007); at one end the disavowal of reality as suggested by Freud, at the other an appropriate mechanism for coping with uncertainty.

Denial in cancer has been shown to have a negative impact and lead to delays in diagnosis (Smith et al. 2005) but it has also been recognised as a coping mechanism (Livneh 2009; Penson et al. 2005). Elisabeth Kübler-Ross’ (1970:35) work on death and dying has been used as a model of grief associated across all parts of the cancer pathway and she considered denial to be a ‘healthy way of dealing with (an) uncomfortable and painful situation’ used as a way to be able to pursue life. Part of the difficulty with not having a clear definition, is that other psychological processes can be confused with denial and Lazarus (1998) warns that it is easy to confuse denial with avoidance. Salander and Windahl (1999) also differentiate between denial and avoidance; avoidance being the recognition of a fact by the patient who then chooses not to talk about it (Lazarus 1998).

Participants in this study described recognising their own denial before the cancer was diagnosed, potentially used avoidance by not referring to the disease by name and reconceptualised the disease as non-malignant in order to ‘pursue life’. Initial denial of symptoms was short-lived because of the urgency, persistence, or nuisance factor. Denial in this study was primarily used as a coping strategy to deal with the anxiety associated with the impact of the cancer diagnosis and as a way to move forward and be able to live in the shadow of cancer by potentially redefining
the disease as not 'real' cancer. However, the participants in this study all presented themselves for treatment and agreed to participate in a study of endometrial cancer; this would suggest that any denial had not become a dysfunctional rejection of the fact of having endometrial cancer.

8.4.7 Implications for Practice

Unlike other tumour sites, gynaecological cancer is primarily concerned with the diagnosis and treatment of four distinct cancers, vulval, cervical, ovarian and endometrial (Department of Health (DH) 1999). Of all the gynaecological cancers, endometrial is the one associated with the highest cure rates and with what could be considered the most straightforward treatments in the form of surgery which is routinely carried out for benign disease. As a result, the psychological impact of the disease on these women can be overlooked.

Research into the psychological impact of gynaecological cancers in general is sparse and there is very little research into uterine or endometrial cancer specifically. What does exist, tends to concern the psychosexual impact of gynaecological cancers in relation to radical surgery, mutilating surgery, pelvic radiotherapy and / or loss of fertility (Hersch et al. 2009). This study has raised the potential significance of the cancer diagnosis on women with early endometrial cancer and the complexity and depth of the emotions associated with the disease, even though the cure rates are high and the surgery classed as 'simple'.

Endometrial cancer surgery is the only major gynaecological cancer surgery that can be carried out in a diagnostic unit (National Cancer Action Team 2008). While the diagnostic team may have training in managing the diagnosis of women with gynaecological cancer, the surgical ward staff may not and the majority of women accessing the surgical services will have benign disease. Cancer related
psychological support services are often concentrated around patients who have advanced cancer and found in specialist cancer centres; there is no requirement in the NHS to provide these services in diagnostic units (National Cancer Action Team 2008). The opportunity to appropriately support these women may be missed and specialist nurses in the diagnostic service, who are not required to have oncology training, may be unfamiliar with the issues associated with having cancer and seeing oneself as a cancer patient.

Even within cancer centres, surgical services and gynaecology are often in clinical directorates where the main focus is not cancer. Having cancer was the overriding concern for women in this study and its effect influenced interactions with healthcare professionals. It is also possible that the reconceptualisation of the disease as something less significant than cancer could inhibit women seeking support or raising their concerns with their healthcare providers. These findings can be used to explore the psychological support available to women with endometrial cancer, especially at the time of diagnosis.

There are currently no recognised dedicated national support groups for women with endometrial cancer. Local diagnostic units and cancer centres could consider how women access support from other women in this situation. Given the significance of cancer to the general public and the anxiety seen before diagnosis, the impact of atypical hyperplasia on women who are managed on a cancer diagnostic pathway with the associated fear, anxiety and rapidity of treatment could also be addressed.

8.5 The Surgeon

It was within the context of fear, anxiety, uncertainty and loss of control that the participants were referred to the surgeon who was portrayed as having the
knowledge and skills to cure the disease. The participants referred to a lack of choice, or any real choice about having treatment.

8.5.1 Choice

Although, offering and delivering choice in healthcare is seen as crucial in improving NHS services as discussed in Chapter 2, definitions of choice are complex and for the individual reliant on perception, which may have little or no impact upon quality of life (Jansen et al. 2004). The participants in this study expressed perceptions of no real choice because they felt that the cancer needed to be removed to survive, or at least Hobson's choice, where both options are undesirable but one is unacceptable: to have surgery or to die.

The concept of 'no choice' in cancer treatment was also described by Ziebland et al. (2006) in a qualitative study of women with ovarian cancer and by Bullen et al. (2009) in men with penile cancer. Markovic et al. (2006) considered fear of dying from cancer as one of the most influential factors in treatment decisions for women with gynaecological cancer and Salkeld et al. (2004) identified survival as the primary concern for 13 patients with colorectal cancer up to two years from surgical resection. Even in benign disease, the sense of 'no choice' can also be seen when symptoms persist to limit daily activity to a level where surgical treatment is necessary and the choice not to have surgery is no longer a viable option (Barthelsson et al. 2003). Even though the participants described having no other viable choice, the decision to have surgery was expressed as an active decision. The decision to act has been described as involving the setting aside of doubts and taking a 'leap of trust' in order to go forward and be able to have treatment (McKneally et al. 2004).
8.5.2 Trust

The concept of trust has been discussed through the disciplines of philosophy, sociology and psychology. According to the psychologist Erik Erikson, confidence in the reliability of others forms part of basic trust in early child development but trusting relationships also define our societies and involve risk above logical calculation and being vulnerable to having our trust abused or misplaced throughout our lives (Baler 1986). Social theory has addressed the complexity of trust in society and in health systems. Human beings are considered to have a need to control their environments in order to minimise the potential for things to go wrong and to maximise the potential for positive outcomes. When achieving this is beyond one’s own individual abilities, Luhmann (1979) suggests the potential mechanism by which control is regained is to place one’s trust in another with the ability to affect a positive outcome. Therefore, trust is a mechanism by which individuals can obtain a feeling of control.

According to Luhmann (1979), modern society is so complex that individuals are forced to reduce the complexity by using trust. Placing trust in another increases control by reducing feelings of uncertainty because the individual no longer has to consider all the confusing alternatives (Giddens 1990). This would mean that trust is only required when individuals are not acquainted with the necessary knowledge to ensure a positive outcome or do not possess the physical capability themselves.

Trusting relationships are typically found where there are conditions of risk, uncertainty and vulnerability (Axelrod & Goold 2000). In a concept analysis of trust, Hupcey et al. (2001) defined the need for healthcare services, which renders the individual dependent and vulnerable, as an antecedent for trust. Where the situation
is more serious and / or the knowledge or skills deficit is greater then there is a greater need to trust (Luhmann 1979).

Participants in this study described having little or no knowledge of cancer or laparoscopic surgery and they had also described a loss of control of their bodies. This combined inability to control their environment would, according to Luhmann (1979), lead to the need to trust the surgeon to affect a positive outcome, that is, to restore health, certainty and control. This basic need was potentially heightened by the serious nature of the underlying illness, fear, anxiety and messages from the process of referral to act quickly which, as Hall (2003), described does not allow time to process the complex information. Trust placed in the medical professional forms a central part of the doctor-patient relationship and the experience of the illness,

8.5.2.1 Trust in Medical Professionals

Within health systems two main forms of trust have been described; 'institutional' and 'interpersonal'. The ways in which a doctor can inspire trust are as an individual, as a representative of the healthcare system or in a combination of both. Although Meyer et al. (2008) argue that concepts of trust are poorly understood and more intricately interwoven than is current understanding, they suggest interpersonal and institutional trust are interdependent, whichever may need to come first.

Interpersonal trust, the decision to trust someone or not, is generally regarded as being negotiated between individuals (Meyer et al. 2008). However, it has been recognised that surgeons often have little time for a bond to develop and patients can be forced to trust the implicit nature of the surgeon’s knowledge and skills (Axelrod & Goold 2000). Although the participants in this study associated their faith in the surgeon to the ‘man himself’, the level of contact with the surgeon and the
nature of the surgeon-patient relationship were such that this trust may have primarily been in the ‘surgeon’ as a concept and that trust was based on trust in the system that created the individual with the knowledge and skills. This is not to suggest that the surgeon could not damage the perceived trust in any face-to-face encounter but that encounter may not be necessary to establish trust. This was demonstrated when some participants had not met the surgeon prior to taking the ‘leap’ to trust him.

Trust has also been suggested to be dependent on prior trust in the healthcare system (Meyer et al. 2008). However, several of the participants in this study described unsatisfactory encounters with other practitioners on their path to the laparoscopic surgeon and although they had lost trust in other parts of the healthcare system or individuals, this did not alter their trust in this surgeon, or at least their need to trust this surgeon.

The decision to ‘trust’ hinged on the fear of cancer, loss of control and the need to be rid of the disease and/or symptoms through surgery. Participants described having no ability to affect this outcome without turning to the figure of the surgeon. The figure of the surgeon together with modern medical technology, were described with reverence and omnipotence; having the power to control the future outcome. Trust in the surgeon was inextricably linked to the power of the surgeon and the perception of the role and ability of the surgeon.

8.5.3 Power

Power is essentially the measure of the ability to control one's environment or that of others. Although power is a contested concept with no agreed definition, it encompasses notions of personal ability, having a controlling influence on others and being given 'office' or authority. Power and powerlessness were referred to by
participants in this study both directly and indirectly in the relation to the disease and the treatment in the hands of the medical professionals. Although closely linked to control, power in this context relates to the ability to influence, the balance of power in a relationship and social power.

Participants in this study described the recognition of illness and the need to seek help from a ‘powerful other’. Trust in the medical professional is potentially obtained through this vulnerability and the recognition of expertise and knowledge but it is also linked to authority and social control which work together to establish medical power (Salter 2004). Hall (2003:53) argues that the ‘absolute economic and social power of medicine increases daily’ and that medicine has become so powerful that it has taken over our lives.

The rise of medical power has been traced by many authors, notably Michel Foucault in *The Birth of the Clinic* (1963) where medicine was described as the most powerful vehicle for controlling the individual. The increase in medical power has allowed medicine to define the system of beliefs that represent health and ill health in our society (Parson 1951) and, in keeping with Foucault’s concepts of medical power, this belief system or model has become accepted as the norm which represents reality.

**8.5.3.1 Medical Model**

Modern medicine is considered to concentrate on a model of disease which asserts that only clinically observable symptoms have medical significance, not the subjective suffering of patients, the embodied whole. This model is based upon the assumption that all illness has a single underlying pathology which, if removed, will result in health (Wade & Halligan 2004). It affirms the body as object rather than
lived subjectivity, effectively separating the body from the person, and is a form of disembodiment.

The birth of modern medicine saw the 'hands off' academic approach of the early physicians shifting to the manual skills required to identify and observe disease within the body (Jewson 1976). Leder (1990:146) described modern medicine as 'profoundly Cartesian in spirit', separating the mind from the body which becomes an object to be repaired. This objectification of the body effectively dehumanises it: the gaze of another no longer seeing the person within the body, making it open to manipulation and control. This in part has been referred to as the clinical or medical gaze (Foucault 1963).

The management of the sick has moved from the home to institutions with the capability to fragment the body and examine it down to the very cells it is composed of (Foucault 1963; Jewson 1976). Surgeons have been at the centre of this progression to disease being managed in hospitals because of technological developments in anaesthesia, asepsis, antisepsis and in a reduction in pain and infection which were the main reasons that early surgical attempts resulted in death (Lawrence 2006). These developments in medicine have led to the increasing value placed upon the skills of the surgeon gazing deep into the body and repairing or removing the broken parts.

Surgeons are now arguably perceived as the most technically skilled of all medical practitioners and the invasive and potentially life-threatening nature of surgery shapes the relationship between surgeon and patient (Axelrod & Goold 2000). Jewson (1976) considers the shift from bedside medicine to hospital and laboratory medicine as representing a shift from being a person-orientated discipline to being object-orientated. This lack of control and influence by the person, now
deemed ‘patient’, has been described as existing in all medical consultations and interactions but can be demonstrated in the operating room, where patients are ‘operated on’. Individuals considering major surgery are required to become object and transfer total responsibility during an operation, not least because most are unconscious. Even when they are conscious, it is unlikely that they can influence a procedure as it is taking place.

Women in this study described this process of objectification as being on a ‘conveyor belt’ and ‘just another person’ being ‘done to’ and ‘acted upon’. However, patients have also been shown to objectify their own bodies as a mechanism to cope with disease and clinical examinations, especially in association with intimate examinations. Joan Emerson (1970) described a process of objectification of the body during gynaecological examinations which depersonalised the interaction, shifting the balance of object and subject throughout the examination. She argued that this allowed the examination to take place without compromising social reality and accepted norm. Allan (2005) explored the experiences of infertile women whose acceptance of the medical model was a way of understanding infertility and being able to have a child. The women experienced their infertile bodies as object, acted on by medical technologies and consisting of bodily parts but also as subjective lived body during the experience.

For women in this current study, the uterus was seen as diseased object to be removed but the experience of having cancer existed outside of the uterus to incorporate the whole person and sense of self as changed. The women in Allan’s (2005) study recognised but coped with this process of objectification and the women in this study also described readily giving themselves as object to the power of the expert surgeon, in order to be cured.
8.5.3.2 Medical Knowledge

Foucault (1975) considered power to be intimately linked with knowledge, suggesting that one does not exist without the other. The traditional doctor-patient relationship has been described as a paternalistic model where the doctor has exclusive control on the definition and disclosure of relevant medical knowledge and the patient accepts the authority of the doctor in a unilateral power relationship (Salter 2004). Within this model, medicine has come to ‘own’ knowledge about disease and disregard the subjective experience of the patient’s illness. This is potentially compounded by Lukes threefold model of power (A forces B to do something; A controls the agenda in interaction with B; A controls the world that B sees) where the doctor has constructed the world-view of disease as the patient sees it (Canter 2001). These factors create a balance of power in favour of the doctor which means that in any interaction the doctor is active and the patient passive (Salter 2004).

The surgeon, not only possess the shared knowledge and world-view of the medical professional but also has a manual skill set perceived to be above that of other doctors (Hall 2008). In this study, the laparoscopic surgeon was also identified as more expert than his peers, both medical and surgical. This concept was introduced and reinforced by the system of referral from generalist to specialist and from specialist to super-specialist, that has come to represent the way cancer services have been configured in England with the introduction of The NHS Cancer plan (Department of Health (DH) 2000b) as discussed in Chapter 2 and in the Policy Review described in Chapter 12.

These factors potentially contributed to setting the figure of the surgeon apart as the sole person with the knowledge, skills and power to ensure the required positive
outcome. However, successful completion of the surgery would affirm that the participants trust had been rightly placed in the power of the surgeon and the perception of this in retrospect, strengthened. This could explain the high level of trust in the surgeon as it was recalled after the ‘successful’ procedure.

In the cancer literature, colorectal cancer patients rated trust in the surgeon and confidence in specialty training of paramount importance and also highlighted the need for the surgeon to have specialist knowledge and be up to date (Salkeld et al. 2004). Burkitt Wright et al. (2004) suggested that it is the enduring characteristics of the doctor that matter to patients. Women with breast cancer in their study, valued doctors who were technically expert and whom they respected. The study used a mixture of surgeons and oncologists but most of the patients had surgical consultations and it may be that the surgical encounter is different to other encounters, especially in cancer, where surgery still represents the most effective cancer cure, as previously discussed. Although there was some discussion in the literature about the surgeon / patient relationship, most studies exploring the doctor / patient relationship considered ‘doctors’ as a generic group.

Medicine has traditionally been given quasi-ecclesiastical status and surgery remains possibly the most ritualistic of all medical practices which has been directly compared to a religious ceremony. In a phenomenological self-reflection Daniel Hall, a surgeon and priest, considers the similarities of his role as a priest at the altar of God, to his role as a surgeon at the altar of the operating table (Hall 2008). He describes the absolute power of the surgeon when he says:

‘in the face of the awesome power extended to me by my office. This man needed the particular care of the surgeon's knife, and I was the only one available to wield it’ (Hall 2008).
The power obtained through the development of expert skills and a discrete body of knowledge that is controlled by the profession, is legitimised by social structure to give medicine the authority to exert control.

8.5.3.3 The Sick Role

Foucault (1963) suggested that it is belief systems that define what is normal and what is considered deviant in society. In Talcott Parsons' (1951) view of modern society, disease was described as a form of social deviance and the patient objectified as a victim of circumstance with little or no responsibility for his/her disease. In this model, society recognises disease as a deviant, undesirable state and delegates the power and authority to protect society to medical practitioners. The State legitimises this power and, in recognition of their expert knowledge, allows medical professionals to regulate themselves.

Talcott Parsons was the first sociologist to describe the role of the 'sick' in modern society and described two models of illness; one as a failure to keep well and the other as deviance to an undesirable state (Bury 2004). Parsons' (1951) theory of the 'sick role' relates to the sick being cast out of society because they are no longer able to perform their function and the need for reintegration into society for social order to be maintained. The doctor-patient relationship requires the patient to take on the 'sick role' and once designated as such, is excused their required role in society on the condition that expert help is sought to return to health. The doctor is given the autonomy and authority to return the 'sick' to health, back into their role in society. The doctor is trusted to act in the best interests of the patient to achieve that aim, establishing the paternalistic relationship with the doctor as 'father' and the patient as 'child'.
Although, the Parsonian doctor-patient relationship has been criticised for not reflecting the complexity of ill health especially in relation to long term conditions (Hughes 1995 online; Schilling 2001), it remains the theory which places social responsibility with the sick to seek help to become ‘well’ and legitimises social power for the doctor. In this study the women appeared to take on the ‘sick role’ by entering into the Parsonian contract with the medical professionals in exchange for being made well again, or at least not dying from cancer. This passive role was described most acutely in relation to the surgeon and immediately postoperatively, as being taken care of and looked after. However, for the patient, the decision to become passive in the hands of the experts could also be described as an active mechanism for maintaining control, as previously described.

The other consideration in relation to power that may be relevant in the relationship between the women in this study and the male surgeons who treated them, lies within gender politics.

8.5.3.4 Feminist Theory

Feminism is a philosophical and political movement which concerns the social, political and cultural equality of the sexes, generally concentrating on the inequality and oppression of women. Feminism does not seek to understand essential truths about reality but challenges attitudes and ideas that hurt women (Stevenson 2002). There are four traditional orientations of feminist theory: liberal, Marxist, radical and social, together with the more recent black feminism and queer theory (Kralik & van Loon 2008; Stevenson 2002). Feminist epistemology concerns situated knowing; the concept of gender affecting all aspects understanding, of being-in-the-world as a woman. It has been argued that because the accepted world view is controlled by men, women are disadvantaged. Simone de Beauvoir (1949) considered society to
be defined by male experiences and that women represent 'other', the deviation from the male norm to which everything is compared. Feminist theories are interwoven with theories of power and social control. In health this has concentrated on the rise of medical power over the traditional female healers (often labelled as witches), the medicalisation and legal control of women's bodies and the dynamics of the doctor-patient and doctor-nurse relationship.

Endometrial cancer is a condition which exclusively affects women. It is a disease of the female reproductive anatomy which is central to concepts of radical feminism and the sexual and reproductive objectification of women. Removing the uterus has long been associated with female oppression since it was first described as a treatment for female emotional behaviour, possibly linked to the menopause or what is now called pre-menstrual syndrome, then defined as 'hysteria' (Sutton 1997), hence the term hysterectomy or removal of hysteria. Feminists question the use of hysterectomy to treat pathology based upon age: if the uterus is no longer 'needed' for childbearing then the threshold for recommending hysterectomy is significantly reduced (Dalla Costa 2002). Cancer is often excluded from feminist discussions about hysterectomy because it is generally accepted that the use of surgery remains the most effective form of cancer treatment and that survival is the primary aim of cancer treatments where possible, as discussed.

The women in this study did not generally question the need for the uterus to be removed and objectified it as a diseased organ which needed to be taken out to save their lives. The only exception was the woman who had preinvasive disease who expressed regret at the unnecessary loss of her uterus which was to do with her 'body and soul' 'as a woman'. She did, however, add that she would have
considered the loss of her uterus as an acceptable trade off for a cancer cure if her final pathology had not confirmed her disease as premalignant.

However, there has been a recent trend towards conserving the uterus in women with endometrial cancer under the age of 40 years (Navarria et al. 2009). Treatments which do not involve surgery in gynaecology are commonly referred to as fertility-sparing or fertility-preserving, implying that the uterus is only to be protected for its childbearing capacity and restricting the use of such treatments to women of childbearing age or inclination. There is no evidence to suggest that endometrial cancer differs in its biology in younger women so the restriction of the use of non-surgical treatments could represent an example of the way in which women continue to be covertly oppressed in the healthcare system.

The women in this study did make reference to what feminists see as the oppressive patriarchal system created within medicine and institutions, as discussed earlier. This tended to be described more in relation to other doctors or nurses than the laparoscopic surgeon who maintained the aura of ‘powerful other’ beyond reproach. John Stuart Mill (1869) argued that women did not need ‘taking care of’ like children but life threatening illness saw the women in this study describe the need to be taken care of by a ‘powerful other’ in the form of the surgeon. They also valued nurses who were caring or nurturing.

Emerson (1970) discussed the degendering of roles in gynaecological consultations and examinations. The women in this study made reference to their satisfaction with their male surgeon (gynaecologist) as an individual but some regret about not always being able to choose a female doctor. In Western countries, evidence for a preference of female doctors in gynaecological care is generally not supported. Fisher et al. (2002), Johnson et al. (2005) and Makam et al. (2009
 reported that the majority of women have no strong preference for a female gynaecologist and although Schmittdiel et al. (1999) demonstrated a preference for a female doctor in over 50% of the participants, another 42% had no preference. The two most common reasons cited for preferring a female doctor, were issues of personal modesty and the perception that a female doctor would understand the gynaecological problem better.

Female support was generally discussed in relation to ‘who to tell’ and in the relationship with other healthcare providers, primarily nurses. Identifying gender issues in supportive interventions by nurses was difficult because most nursing interventions providing support, involved female nurses by virtue of the fact that most nurses are female (according to questions in the House of Commons in 2007 (online) only 11.1% of nurses registered in the UK were male) and gender of practitioners is not often alluded to. However, there is evidence to support the view that female patients prefer female nurses, especially in areas of practice where the degree of intimacy is high, such as gynaecology (Chur-Hansen 2002) and that female nurses act in a way that recognises the subjective experience of the woman (Lawler 2006). However, for Allan (2005), nursing continues to deny the emotional context of the illness and medical encounters, reinforcing the patriarchal system created by male doctors.

In this study, patients primarily wanted survival and this has been reported as the driver of the experience for other cancer patients (Salkeld et al. 2004). The infertile women in Allan’s (2005) study described the experience of the body as an object acted upon through medical technologies as less traumatic than feminist literature would argue. It may be that the way to acquire the required positive outcome, be it survival or having a child, is to actively adopt the ‘sick role’ and
comply, which may not be perceived as disempowering to the women who choose it.

Bem (1993) would argue that hidden assumptions are so embedded in our social and cultural discourse to perpetuate male power and that we experience the world through the lense of gender and are no longer aware of its influence and Lukes model (Center 2001) would identify the women in this study as seeing the word according to the surgeons view, as expressed in their mirrored descriptions of the surgery. It becomes difficult to separate issues of gender in this study because of the power concepts already inherent in medicine and the exclusively female patient population in gynaecology, together with the male surgeons. Whether the women objectified their uterus because the medical model objectified it, or because this was as a necessary coping mechanism is beyond the scope and data in this study.

However, whatever the underlying power dynamics, the women in this study described trusting the surgeon as someone who would protect their interests. This is considered to be an important component in patient trust (Mechanic 2008). Salkeld et al. (2004) reported that patient trust, forged in the clinical encounter, was a feeling that the surgeon understood, cared for and respected them. It remains possible that, given the limitations of the preoperative clinical encounter with surgeons, the trust already engendered in the specialist surgeon is part of the doctor-patient power relationship and the need to trust in a situation that would otherwise be out of control.

As a result of the perception of having no choice and the decision to trust the expert person of the surgeon with the knowledge and skills to effect the desired outcome (the cure for the cancer), the participants described making the decision to
transfer the responsibility for ‘oneself’ to the knowledgeable and powerful surgeon. This included treatment decision making.

8.5.4 Decision Making

With recent attempts to move away from the medical paternalistic model of healthcare, choice is considered to be the way to empower patients, giving them the ability to make decisions about their care, independent of the healthcare practitioners, as discussed in Chapter 2. However, decision making is a complex phenomenon which is linked to feelings of power, control, uncertainty, level of responsibility and potential outcome. Toombs (1993) suggested that only the patient can gauge whether a medical intervention is sufficiently disruptive to cause personal suffering. However, in the presence of serious illness, it is usually the doctor who possesses the power, knowledge and skills to treat the disease, as discussed. Although the concept of shared decision making is considered an improvement from paternalistic models in healthcare, individuals with cancer have been shown to find the concept of choice and decision making in cancer treatment to be inappropriate and untimely (Burkitt Wright et al. 2004; Markovic et al. 2006; Ziebland et al. 2006). Hall (2003) described not having enough information to be able to make informed decisions and consequently chose the treatment modality for her breast cancer because she 'liked the radiation oncologist'.

Ramfelt and Lützén (2005) defined two different approaches to participation in decision making for treatment compliance; compliance with participation and compliance without participation. They concluded that complying without participation was associated with feelings of uncertainty, distress and a lack of trust. However, Kraetschmer et al. (2004) concluded that passive patients, that is, those
who would be seen to comply without participation, had higher levels of trust than those who preferred an autonomous role.

Participants in this current study could be described as having adopted a passive attitude to decision making, in keeping with the 'sick role' and as described by Elkin et al. (2007) and Leydon et al. (2000) in relation to cancer patients. However, they could also be described as being empowered by taking the decision to hand over the responsibility for their disease and treatment to the surgeon and Aujoulat et al. (2007) and Fallowfield (2004) argue that the decision to be passive should be considered a form of empowerment. Mishel et al. (1988) also considered the transfer of responsibility to a 'credible authority' as a mechanism for empowerment, by reducing uncertainty because the uncertainty that exists is actively passed on to another. In serious situations, such as having cancer, this credible authority can include faith in a God and / or faith in a surgeon and may also explain some of the religious language used in reference to the surgeon.

However, this study highlighted several factors in the complexity of decision making for women with endometrial cancer. The first point considers the decision that participants perceived as being made. Kraischmer et al. (2004) differentiated between what they called problem solving and decision making. They considered problem solving to be where there is only one correct answer, using the example that, if a leg is broken on x-ray it remains broken, regardless of patient preference. In this current study, once cancer was identified as the problem then the solution was presented as the need to have surgery. The knowledge and skills required were identified as beyond those of the participant and in the domain of medicine and the surgeon, so responsibility for care was handed over to the surgeon, in keeping with the Parsonian 'sick role'. At this point it could be considered that all other surgical
decision making, for the patient, was immaterial, since it was now the responsibility of the surgeon. Indeed, it could be seen as counterintuitive to make the decision about the surgeon being the only ‘credible authority’ to take control and reduce uncertainty, only to reintroduce uncertainty by considering that the surgeon may not actually know what surgery was best by offering choice. 'Surgeon's recommendation' has been shown to be the most influential factor in decision making prior to gynaecological cancer (Markovic et al. 2006) and breast conserving surgery (Lam et al. 2005).

Barry Schwartz (2004) in his book The Paradox of Choice considers this dichotomy in modern healthcare when the key to choice is considered to be the transfer of decision making from someone, who essentially knows, in this case the surgeon, to someone who knows nothing, the patient. Schwartz (2004) believes this to result in the reduction of choice. It is this complexity in cancer that needs to be recognised and is possibly why cancer policy fails to deliver on promises of treatment choice, as discussed in Chapter 2. Cancer exists as an acute and chronic illness and participants in this study were in the acute phase with a perceived ticking clock on a window of opportunity for cure. Although, Hall (2003) considers the ‘rush’ to treat in cancer care a deliberate manoeuvre to maintain medical power and can be seen as the reality perceived and conveyed by medicine, it remained beyond the knowledge of the participants to treat the disease.

It could be argued that the participants were given no option but to hand over responsibility to the surgeon but this was not their overriding perception of it. In the validation interview agreement was sought for each of the formulated meanings linked to this theme which led the participants to agree that, although in their opinion their trust was freely given, it was as a result of their perception of having no other
option or choice as uncovered in the analysis of the interviews. Shaha and Cox (2003:194) also identified colorectal cancer patients as being unable to make decisions on their own; they described the omnipresence of cancer shifting power from patients being able to make their own decisions relating to the treatment of the disease and 'giving up their locus of control to others', rather than feeling forced to relinquish it.

It is has been assumed that the elderly prefer to be passive in treatment decision making and Elkin et al. (2007) studied cancer patients aged 70 years and above and found 52% preferred the passive role. However, one could argue that even though endometrial cancer is more prevalent in the elderly, it is simply a feature of the issues surrounding the disease and required care that are the antecedents to trust in this scenario.

The other effect seen in the study was that of offering the surgery and then adding that it may not be performed. This had two effects: one was to reinforce how difficult the operation could be, confirming the expertise and power of the surgeon, and the second was to potentially make it more desirable. According to Robert Cialdini (2007) scarcity forms one of the ‘weapons of influence’ and offering laparoscopic surgery and then suggesting that it might not be possible to perform it, could be seen as having the potential to increase desirability. Fear of losing out on something is described by Cialdini (2007) as a powerful motivator in making the object more attractive. Having had the intended surgery, the participants in this study expressed relief and a sense of being fortunate or lucky at being able to have the surgery which may have been influenced by this concept.
8.5.5 Implications for Practice

Paternalistic healthcare, where patients are passive recipients of care, has recently been challenged and deemed to be a thing of the past by government and the general public in favour of more choice, shared decision making and a reduction in the authority of medicine. It has been discussed that the messages are mixed in cancer where there are recommended treatment pathways that do not allow for flexibility and choice (Chapter 2) and where the paternalistic model of medical care potentially remains dominant because of the greater risk and skills deficit.

What this study acknowledges is that for these women, having cancer affected the ability to deal with information and make complex choices with potentially life and death outcomes. This complexity may be more relevant at the time of diagnosis and also in the surgical consultation where the understanding of cure rests heavily on surgery and the skill of the surgeon. Pellegrino (1981) suggests that, because the ill person lacks the knowledge or skills to heal and must seek the help of one who knows how to heal, this relationship will always be an unequal one.

Without acknowledging the true dynamics in the relationship between a cancer patient in need of a life saving operation and a surgeon who can perform that treatment, we may fail to offer patients appropriate support. If patients who are looking for a 'credible authority' to reduce the uncertainty associated with the disease, are faced with options on surgical techniques they may find difficult to understand given the circumstances, then as clinicians we are potentially failing in our duty of care.

The enduring characteristics of the surgeon, that have been discouraged in the recent approach to communication skills in patient care, may be the characteristics required to engender trust and a feeling of security in a serious
situation, as identified by Burkitt Wright et al. (2004). Being able to communicate confidence in one's expert surgical skills should arguably be the focus of surgical communication rather than trying to communicate uncertainty, especially when surgeons are unlikely to undertake surgery that they personally feel is inappropriate, given the potential risks and medical ethics of 'do no harm', as described in Chapter 5. Surgery, as a specialty, is less likely to involve equipoise, which is thought to explain the paucity of surgical Randomised Controlled Trials (McCarthy et al. 2008), discussed in Chapter 3.

This, however, creates a problem regarding the structure of surgical services, where laparoscopic surgeons potentially favour laparoscopic surgery and non-laparoscopic surgeons are unable to perform the procedure. Despite vaginal hysterectomy being the recommended route for hysterectomy in benign disease, the vast majority of hysterectomies are still performed abdominally because of surgeon preference (Domingo & Pellicer 2009). If the recommendations of the surgeon are regarded as the most influential factors for women facing cancer surgery (Lam et al. 2005; Markovic et al. 2006) and surgeons are influenced by their own preferences, then it could be argued that women should be given information before meeting the laparoscopic or non-laparoscopic surgeon if any attempt is made to increase decision making in the surgical oncology context.

Alternatively, accepting that there is little to offer in the way of choice regarding treatment means that the focus of choice can move to areas in which it can be achieved. Aujoulat et al. (2007) consider concentrating on situations that can be controlled to gain a sense of security and reassurance. By concentrating on areas of real choice, clinicians may be able to improve on feelings of hopelessness as
demonstrated in the Arden House study where redefining choice in a perceived helpless situation led to improved quality of life (Langer & Rodin 1976).

8.6 Information Needs

The information needs of individuals with cancer is a relatively constant theme in the literature and information is a major concern on the political agenda because it is seen as the key to achieving Government promises of delivering choice in the NHS, as discussed in Chapter 2. However, the findings of this study illustrated the complexity of the concept of choice as experienced by women with early endometrial cancer and the theme identified concerning information and support, serves a function separate from information influencing knowledge, choice and decision making, which has been primarily discussed in relation to the surgeon.

Fallowfield (2001) suggested that a distinction should be made between a desire for information and a desire to assume responsibility for decision making and understanding medical knowledge. It was this distinction that was alluded to in this study. Participants saw information as an important part of the experience and also identified a lack of information. However, this information centered on entering a world of the unknown, as someone who was frightened and uncertain, with a diagnosis of a potentially life threatening disease. Information focused on creating familiarity in an unfamiliar situation and environment; this was an individual need, based upon prior experience and knowledge.

Philosophically, these findings concern the individuality of patients and their unique need for information and understanding. For Heidegger (1962), humans exist in a world surrounded by other humans but they are characterised by their uniqueness which gives rise to individual potential but it is also the way that we may fail to understand each other. Therefore, as individuals we participate in cultural,
social and historical shared concepts of the world but our individual understanding differs based upon our own prior experience, knowledge, social groups and culture. It was this uniqueness that was described by participants in this study.

Individuals who access healthcare services bring with them their own perspective and understanding of the world. Following a cancer diagnosis, they will have also departed from an understanding of illness in the abstract or theoretical, to an understanding of what Toombs (1993) described as illness-as-lived, or in this case cancer-as-lived. The move from what is known and understood as a well person without cancer into an unfamiliar environment (both internally with a complex disease process that is not fully understood and externally in the clinic and hospital), has the potential to create anxiety and distress linked to states of uncertainty, which can be addressed with adequate and appropriate information (Mishel & Braden 1988).

8.6.1 Familiarity

A diagnosis of cancer has been discussed in this chapter, as a stressful life experience shadowed by fear and anxiety. During this time individuals are required to assimilate information about the illness and treatment, not least to comply with informed consent (Department of Health (DH) 2009c). Participants in this study expressed the difficulty this imposed upon them and the responsibility for the specialist knowledge required to understand the complexity of the disease and to decide upon the most effective treatment was given to the professionals. It was the lack of knowledge about what would happen and how to cope, that caused the most concern for participants in this study.

Uncertainty has been previously described as increasing psychological distress and Shaha et al. (2008) reported that uncertainty could be triggered by insufficient
and inadequate information. Mishel and Braden (1988) suggested that, not providing enough information leads to uncertainty by denying the individual the ability to form a frame of reference and Mishel et al. (1984) demonstrated better adjustment and a more positive attitude to the future when women with gynaecological cancer were given more details of their illness.

Participants in this study expressed a desire for more information, some wanted more detailed information than others but none wanted anything more than, what to expect, what to do and how to cope in the unfamiliar environment of the hospital. Many factors have been considered to influence information needs and it has been suggested that older people prefer less information (Elkin et al. 2007; Pinquart & Duberstein 2004), which would be especially relevant in endometrial cancer. However, with the exception of those who wanted a more active role in decision making, Ankem (2006), in a systematic review, found no evidence to suggest that any one group or ‘type’ of individual required more information over another.

Developing a sense of understanding of the process, allows individuals to take some control of the uncertainty by becoming familiar with the process to which they have already committed. Participants in this study associated information with this level of control and reduction of uncertainty. It is information this that researchers such as Fallowfield (2001), Leydon et al. (2000) and Jenkins et al. (2001) allude to in the discussions around patient information and its distinction from decision making. This type of familiarisation with a process has also been seen in the literature regarding information giving for adequate preoperative and preadmission preparation (Walker 2002).

Information regarding the environment and process of treatment is variable and locality dependent. The internet, as a vehicle for obtaining national and international
information, was described as confusing and may not currently be suitable for obtaining this level of situated knowledge. Given the individuality of the needs of patients, it would seem appropriate to consider tailoring information and the use of tools to tailor information to the individual needs of cancer patients, have been shown to be effective (Hankins & Llewellyn 2008). The individual requirements for information expressed in this study are in keeping with Heideggerian concepts of uniqueness framed within a social and cultural context and the role of family and friends in providing this type of information and support was also expressed.

8.6.2 Support

The individual circumstances of the participants in the study varied but relationships featured as a sub-theme which acknowledged the importance of support from healthcare professionals, friends, family and significant others. Having adequate support has been shown to reduce levels of anxiety. Social support was seen by Mishel and Braden (1988) as contributing to certainty, suggesting uncertainty was reduced in situations of high levels of support. Shaha et al. (2008) found that perceived social support and uncertainty explained a third of the variance in quality of life, in their review of uncertainty in cancer and Bullen et al. (2009) identified support and relationships as one of the themes in the surgical experience of men with penile cancer.

People with supporting families and those in married relationships have been shown to have lower levels of anxiety (Zabora et al. 2001). However, in this current study, support was not confined to partners or immediate family and over half of the participants lived alone. Women are more likely to be living alone with increasing age; in 2007, 30% of women aged 65 years and over were seen to be living alone and this rose to 61% by the age 75 years (Office for National Statistics (ONS) 2009).
This is an important factor in endometrial cancer where the incidence increases with age, as discussed in Chapter 2.

In a study of the families of cancer patients, Edwards and Clarke (2004) demonstrated that similar levels of distress can be seen in partners and offspring as well as patients. Participants in this study described their role in the support and protection of other family members during the diagnosis and treatment. This served to highlight the situatedness of the disease and context in which individuals, situated in the world, accesses healthcare.

8.6.3 Implications for Practice

Women with endometrial cancer in this study described entering the healthcare system with little knowledge of their disease or potential treatment. Understanding cancer and the pros and cons of complex treatments was knowledge that the participants felt unable to obtain, given the anxiety and need for rapid treatment associated with cancer. The responsibility for treatment decisions was given to the surgeon and the professionals, as discussed, but appropriate information can still engender feelings of control.

Current models of communication and information giving in cancer focus on understanding the condition to a level required to facilitate active participation in decision making (Fallowfield 2001). In the cancer Multi-Disciplinary Team (MDT) the specialist nurse is the person most likely to be given the responsibility for the provision of information (National Cancer Action Team 2008), which is often seen as the dissemination of nationally approved information; the NHS Information Prescription Project (Department of Health (DH) 2009d online) relies upon access to standardised written information.
However, it may not be this type of information that is required by the individual patient and an assessment should include what the patient requires as an individual, rather than a patient with a certain condition. Providing tailored information has been recognised and suggested as the most appropriate model for providing information to patients (Elkin et al. 2007; Levinson et al. 2005; Leydon et al. 2000; Salkeld et al. 2004). However, this is time consuming and often not carried out in practice. Given that patients in this study wanted information from healthcare professionals, including the surgeon, the development of local information should arguably be developed by the whole MDT to ensure consistency.

As with other components of this study, the information provision for women with endometrial cancer in a Network may be inconsistent because these women represent the group of gynaecological cancer patients most likely to be managed in a variety of settings and those least likely to have access to specialist cancer services and assessment. Access to female support could also be considered, as discussed earlier, in a disease where there are currently no national support groups. Providing specific local information to help familiarise patients with the treatment process and healthcare environment may not lead to decision making empowerment but it can reduce certain aspects of uncertainty which has the potential to reduce feelings of powerlessness.

8.7 Self-Care

Participants in this study described vulnerability and loss of control associated with having cancer, admission to hospital and undergoing a surgical procedure which limits function postoperatively. This was themed as independence and covered concepts linked to being able to take care of oneself both physically and psychologically. In human development self-care is the move away from the
dependence of childhood to the independence of adulthood and is considered to be a normal process, deviation from which signifies ill health or maladjustment (Winnicott 1960).

Independence and individualism are valued in Western cultures where the individual is encouraged to reach his / her own potential and success is acknowledged as an individual achievement (Stevenson 2002). Independence is associated with notions of freedom, choice, control, self-determinism and empowerment. However, although individuals are unique, as Heidegger (1962) suggested they also exist in a world surrounded by others and 'all people...are dependent on each other through a variety of social systems for physical and emotional needs to be met' (Plath 2008:1353). Therefore, defining independence is complex and deeply philosophical when contemplating if it is ever possible for humans to be truly independent.

Plath's (2008) qualitative study of 29 elderly nursing home residents described five main discourses associated with independence which included: doing things alone, making one's own decisions and physical and mental capacity. Although Plath's study considered independence as described by older people, illness and disease are also associated with the potential for loss of independence. With reference to a German language study using grounded theory to illustrate the impact of colorectal cancer, Shaha and Cox (2003:192 citing Heller 1994) discuss the reported degree of impairment to an individual's life and social world associated with cancer and described four basic categories: 'I am able, I am still able, I am able anew, I can do it new'. It was this sense of being able to do things alone, losing and maintaining that ability and regaining it anew that was described by participants.
through their experience of having cancer and laparoscopic surgery for endometrial cancer.

### 8.7.1 Being Dependent

Not only has cancer been associated with a fear of death, dying and mutilating treatment, it has also associated with a fear of losing independence and becoming dependent (Toon 2007; Penson et al. 2005). In a study of 108 women with gynaecological cancer, 48% feared losing control and 46% feared dependence. Fear of dependence was higher in women with active disease and although, the study aimed to obtain insights into how women with gynaecological cancer ‘interpret their experiences’ but used a questionnaire based partly on ‘physician understanding of patient perceptions’, it illustrated a concern regarding dependence and loss of control associated with gynaecological cancer (Roberts et al. 1997:167).

Dependence has also been associated with medical treatments and people with serious illnesses like cancer have been shown to consider carefully the consequences of treatment and any trade off with independence and loss of physical or psychological functioning. In a study by Fried et al. (2002), of the 226 individuals who completed the survey, 99% would undergo low burden treatment rather than die (burden was measured by length of hospital stay, extent of testing and invasiveness of interventions, including surgery). However, of these, 74% would not have treatment if the outcome was physical impairment and 89% would not have treatment if the outcome was cognitive impairment. Even if the outcome was cure, 11% would not have treatment if the burden was high.

The fear of becoming dependent and not being able to manage alone following the treatment described by participants is significant in endometrial cancer, where the disease is more prevalent in older women, who are more likely to be living
alone, have co-morbidities such as diabetes and problems associated with obesity, as previously discussed. Part of the process of seeking medical advice and undergoing treatment is to accept the help of others with a loss of some degree of control and participants in this study recognised the need for dependence and acknowledged this within the experience. The participants also described dependence associated with the hospital admission and the immediate postoperative period. Lack of personal control and being dependent can lead to feelings of helplessness and powerlessness and are recognised within the NANDA nursing diagnosis framework where powerless is described as a 'state in which an individual or group perceives a lack of personal control over certain events or situations that affects goals or lifestyles (Carpenito-Moyet 2008:569).

8.7.2 Mastery and Coping

Having cancer has been shown to lead to a level of dependence and a shifting of the locus of control (Shaha & Cox 2003). Surgery has also been associated with dependence and during surgery a state of complete dependence is achieved through the use of anaesthesia and techniques beyond the skill set of most patients. In order for the individual to be able to cope with the uncertainty and loss of control in threatening events, Taylor (1983) proposed a theory of cognitive adaption based around a search for meaning in the experience and an attempt to regain mastery over the event and one's life. Gaining a sense of coping and mastery, hinges on personal control (Wallston 2007) and some aspects of the experience, for the participants in this study, were beyond their control, others aspects were transferred to the surgeon and the nursing staff but others were maintained because of the type of surgery.
Physical functioning is less disturbed in endometrial cancer than in other gynaecological cancers (Greimel & Freidl 2000) but the postoperative period remains a time of significantly reduced physical functioning. Rapidly regaining control of physical function after the operation was described by the participants as a positive experience and important for a sense of mastery. Mishel et al. (1984) described control over physical function leading to positive psychosocial adjustment in gynaecological cancer and can be viewed as regaining a livable embodied relationship to the world and others. Shaha and Cox (2003) described a process of disembodiment in the treatment of colorectal cancer and a re-embodiment in the process of healing, achieved through a sense of control over one's body. Women in this study described being bound by functional activities that gave a sense of what Leder (1990) expressed as 'I can' or 'I cannot' do something.

8.7.3 Implications for Practice

Laparoscopic surgery has been associated with the potential to improve quality of life based upon reduced pain, better physical functioning and an earlier resumption to normal activities (Kornblith et al. 2009). However, benefits are modest and not sustained over time when measured using quality of life scales, as discussed in Chapter 3. This study offered insight into the meaning assigned to the benefits of being mobile and relatively pain free after laparoscopic surgery and the impact on the individual of maintaining independence.

Using phenomenology, it has been possible to demonstrate the potential benefits of laparoscopic surgery for endometrial cancer, in a more holistic way. Offering treatments that reduce dependency has the potential to enhance wellbeing, reducing feelings of powerlessness and redressing the locus of control. This is significant in endometrial cancer because of the association of the disease with
older women who are more likely to be living alone with co-morbidities that may threaten independent living.

8.8 Normal Function

According to Heidegger (1962) we feel anxious if we stray too far from the norm, this he called distantiaUtÿ. As humans existing in a world surrounded by other humans we feel the need to conform to our perception of others, their perception of us and the normative expectations of society as a whole (Goffman 1963; Parsons 1951). Society categorises individuals by attributes considered to be normal in order to function in society (Parsons 1951). The impact of having an illness such as cancer threatens that normality and makes us stand out as different from others, different from our social identity and different from our perception of our self (Toombs 1993).

Having cancer and treatment was described by participants in this study, as leading to a disruption of perceived normality which began for most with abnormal vaginal bleeding. Cancer symptoms which cause disruption have been shown to more readily affect behaviour (Smith et al. 2005) and the presence of persistent abnormality triggered help-seeking behaviour in the participants and the move away from prior personal normality. This can also be seen as the time of moving away from social normality, towards accepting the Parsonian sick role and entering into the contact with the doctor to be healed, as previously discussed.

The women in this study identified the overwhelming influence of the cancer diagnosis on the experience of the surgery. They also described being changed by the experience both physically and psychologically and the fear of being seen by others as different. This was demonstrated by the reluctance of some participants to disclose their illness to others and was more prevalent in relation to cancer than
surgery. Participants in a phenomenological study of colorectal cancer described the fear and embarrassment associated with the disease leading to feelings of being different from others and consequently feeling alone (Taylor 2001). This sense of being different and isolated by the association with having cancer has been linked to the stigma of the disease.

8.8.1 Stigma

Stigma refers to the actual or symbolic identification of an individual as being different in a way that is culturally unacceptable or inferior. According to Goffman (1963) stigma was originally used to refer to signs that were cut or burned into the body to identify the individual as a criminal, traitor or slave but it has come to signify the disgrace itself rather than the bodily evidence of it. This transgression from the culturally accepted norm makes those that are stigmatised stand out from others and identifies them as a less worthy 'other'.

For Parsons (1951), it is the recognition of illness as an undesirable state that encourages the individual to seek help. Although the individual is required to see illness as an undesirable state, the sick person is also expected to want to overcome the illness as soon as possible. Part of the Parsonian contract to be healed is the exemption of the individual from being seen as responsible for having their disease. However, Goffman (1963) identified stigma in situations where the individual is deemed responsible and also in situations of degenerative illness, diseases which evoke fear and contagious disease. In situations of stigma, the whole and usual person becomes a tainted one and is consequently discounted as a member of society.

Cancer as a disease is associated with stigma. In keeping with Goffman's (1963) theory, cancer is associated with destructive behaviours such as smoking and over
eating which can then be deemed the responsibility of the individual. Individual responsibility has been linked to Kübler-Ross' (1970) stages of grief, expressed as, “what did I do to deserve this?” Cancer is also feared as a degenerative disease which results in death, as described, and cancer has, wrongly, been considered to be contagious. Recent links with viral infections, such as the Human Papillomavirus (HPV) and Hepatitis, have continued to support this assumption and in the case of HPV there are also links to what has been considered promiscuous sexual behaviour.

Goffman (1963) describes the move away from the external branding of the stigmatised. However, cancer remains associated with mutilating surgery and the alopecia which results from most chemotherapy regimens, has been seen as a physical branding of the patient as one who has cancer (Rosman 2003). The cancer patientliness described by Little et al. (1998) could be identified with the stigma of being labelled as a cancer patient and people with cancer have reported being avoided by others (Howell et al. 2003) and ‘ghettoized’ (Hall 2003). It is possible that the stereotypical image of the cancer patient did not fit with the identity the participants attached to themselves living with the disease and part of the process of reconceptualising the disease as not ‘real’ cancer, could be to avoid the stigma associated with it.

Accepting the Parsonian sick role allows the individual to be temporarily excused from the obligations of society but stigma implies a deeper and lasting change to self-identity. Breaden (1997) suggested that, once treated for cancer, the body is never quite the same as it was before the diagnosis and this change in the body and self was described by participants in this study. Although, the treatment for endometrial cancer does not generally involve chemotherapy or surgery which
would obviously identify the individual as having cancer, the use of laparoscopic surgery reduced the physical signs of having had the disease even further. Cosmesis was considered unimportant for most women in this study but the effect of minimal scarring may be more significant in allowing patients to de-identify themselves as ‘cancer patients’.

Stigma has been shown to be increased when the disease and / or treatment affects sexual function. This has been described as a double stigma (Gray et al. 2000). The intimate nature of the disease and treatment was also discussed by participants in this study and this was associated with embarrassment and a need to conceal. Men with penile cancer in the Bullen et al. (2009) study and men with prostate cancer in the Gary et al. (2000) study, also described not telling significant others about their cancer and surgery.

This deviation from normality and altered perception of self was not visible to others and participants in this study discussed control on the appearance of normality and how this was maintained by deciding who to tell and who not to tell. However, the most significant and obvious disruption to normality and normal function was associated with the hospital admission.

8.8.2 Hospital and Home

Hospitalisation has been associated with a loss of control and a loss of physical functioning (Mishel et al. 1984). Participants in this study described the significant disruption that admission to hospital caused; from aspects of functioning such as constipation and dislike of hospital food to the disruption of being in an unfamiliar environment, as discussed earlier. These disruptions were significant to the participants; affected their families and friends and provided an exclusion from social activities and employment. However, being mobile and having minimal pain was
associated with self-care and independence, as discussed, but it also meant a short hospital stay and a rapid return to normality, with friends and family often unaware that a change had been made. Shaha and Cox (2003) also described a single intervention with rapid restoration as less of an impact on the lives of people with colorectal cancer.

Participants in this study wanted to go home and this has been described as a need to reconnect with the familiar world, even though hospital can be seen as a safe place (Spichiger 2009). However, the palliative care patients in Spichiger's (2009) study also associated hospital with a prison, as expressed by participants in this study.

Being able to work has been described as an important part of social identity (Aujoulat et al. 2007). Despite the association of endometrial cancer with older women, over half of the participants were in paid employment. In this study, the significance of returning to work was not dependent on feeling well enough but was more complex and socially dependent, as seen in the literature review (Chapter 3). Being able to conceal illness from colleagues and not appearing different has been shown to enable normality and the giving up of social activities because of feeling different, as described by Aujoulat et al. (2007), was not identified by participants in this study, perhaps because of the ability to maintain normality.

Participants also associated hospitals with a high risk of infection and an association has been described with an increased risk of Hospital Acquired Infection associated with increased bed stays (Tess et al. 1993).
8.8.3 Implications for Practice

Interventions that have the potential to reduce hospital stay in a department are encouraged as a significant part of current improvements in NHS care and are a feature of commissioning for cancer services in England (Department of Health 2009b online). This is designed to improve patient experience and lead to cost reductions and Cancer Networks could consider the capability of local gynaecological cancer services in delivering on this agenda.

Whilst the participants expressed a lack of knowledge about cancer or the surgery, they also offered opinions about both and generally favoured laparoscopic over open hysterectomy despite very little knowledge or experience of open surgery. This preference for laparoscopic surgery in the absence of evidence was seen in studies by Hart et al. (2001) and Kluivers and Opmeer (2007) and was described in Chapter 3. Given the evidence for patient preference and the potential improvement in patient experience associated with laparoscopic surgery for endometrial cancer, it could be argued that all women should have equal access to this type of surgery. However, it was acknowledged that, in this study, the participant’s descriptions of the surgery mirrored the medical literature and although the media influences public perceptions of cancer and cancer treatments (Clarke & Everest 2006), this could also suggest that the surgeon’s preference had some influence during the consultation.

As ambulatory approaches to cancer become more popular it would also be important to remain aware of the fear associated with the disease and the need for information, support and individual approaches to care if hospital stays and contact with healthcare professionals are reduced.
8.9 Summary of Chapter

This chapter took the phenomenological description of laparoscopic surgery in endometrial cancer and developed a series of key findings on which to base the synthesis of the analysis and the literature on the identified themes. Having endometrial cancer can be associated with concepts linked to psychological wellbeing such as fear, anxiety, loss of control and uncertainty. As a result of the threat of the disease and lack of knowledge, the individual may develop mechanisms to reduce uncertainty and maintain control, such as, trusting the surgeon and faith in the power of modern medicine rather than autonomy, choice and decision making.

Being ill and in hospital has been associated with concepts such as powerless and dependency but being informed of what will happen and how to cope, together with having a surgical treatment that reduces dependency, has the potential for empowerment. Normality has been described by Heidegger as a desired human state and laparoscopic surgery can enhance normality with a reduced hospital stay, rapid return to normal activity and few visible signs of illness.
CHAPTER 9: CONCLUSION

9.1 Introduction

This chapter concludes the research project and presents a summary of the study and findings together with the relevance of this project to patient care and clinical practice. This study has focused on the experience of women having laparoscopic surgery for endometrial cancer but the potential applicability of the findings in relation to other patients, diseases processes or areas of practice have been considered and will be presented here. The strengths and limitations of the study are explored together with suggestions for further research to bring this project to a close.

9.2 What is Already Known on This Topic?

Endometrial cancer is a common cancer that affects women across the world but the highest incidence is seen in Western industrialised nations and the disease is on the increase because of a global rise in the elderly population and obesity. Removal of the uterus is the primary treatment for this disease and developments in laparoscopic surgical techniques have led gynaecologists to be able to perform a hysterectomy using a laparoscope.

Laparoscopic surgery for endometrial cancer is being carried out by some gynaecological cancer surgeons, primarily based in specialist centres. The procedure appears to be safe in the hands of appropriately trained surgeons and is as effective in the management of endometrial cancer as open surgery. The reported complication rates are generally low but the elderly and obese appear to be the group of patients who stand to gain most benefit from this type of surgery.
The reporting on the financial impact is mixed, with suggestions that the laparoscopic route is more expensive than open surgery, about the same or has the potential for cost savings. Quality of life concerns relate to postoperative pain, mobility and length of hospital stay. When researchers have used a quality of life measure, laparoscopic surgery has shown some advantages over open surgery but this is not sustained over time.

This study has described three main stakeholders involved in laparoscopic surgery: the patient, the healthcare professionals (primarily the surgeon) and the providers of services. In the research on this technology the triangle of stakeholders is unevenly balanced in favor of the surgeon. Research focused on the patient perspective is absent from the literature and it was this gap that this study set out to address.

9.3 Summary of Study

This aim of this study was to develop an understanding of the experience of laparoscopic surgery for endometrial cancer from the patient perspective. A phenomenological approach based upon the philosophy of Martin Heidegger was used to develop an interpretive description of the patient experience (Chapter 4). Qualitative data were obtained from a purposive sample of 14 women from two cancer centres in the South of England who had undergone laparoscopic surgery on a specialist endometrial cancer pathway.

Unstructured interviews were carried out between February 2008 and July 2009. The mean age of the participants was 62 years (SD 11.5) and all, except one, were within a year of surgery at the time of the interview. The taped interviews were transcribed and data were managed using Microsoft Excel and analysed according to Colaizzi's (1978) framework for the analysis of phenomenological data (Chapter 229.
5). This included returning to the participants for a second interview to confirm the interpretation of the first and validate the findings.

Five theme clusters were identified and described using the headings having cancer, information and support, independence, normality and transfer of responsibility to the surgeon. The findings suggested that having cancer overshadowed the experience of laparoscopic surgery for women with endometrial cancer and the need for specialist treatment led to the transfer of responsibility to the surgeon for decision making and care. The findings also suggested that information and support needs were personal but information on what to expect and how to cope given individual circumstances, was required but perceived as lacking from healthcare professionals. The findings also supported the view that laparoscopic surgery is associated with a rapid recovery and return to normality, maintaining independence through the capacity to self-care.

9.4 What This Study Adds

Laparoscopic hysterectomy was only introduced in 1988 and, to date, there have been no studies which have addressed this technology from the perspective of the patient. This study was the first step in redressing the balance in information available to women who are offered and undergo this procedure as treatment for endometrial cancer. The unique contribution to the literature is a description of the procedure from the perspective of women who have experience of it.

The findings of this study have identified that the overriding concern for women with endometrial cancer is to be rid of the disease and that they trust the surgeon as expert to do this in the most appropriate way. The study findings highlight the significance of a cancer diagnosis, even in a tumour site which is associated with high cure rates and, therefore, perceived lower psychological morbidity. This study
confirms research which suggests that laparoscopic surgery is associated with a rapid recovery time and return to normal function but it also considers the impact of this from the patient perspective. Finally, this study suggests that the type of information on what to expect and how to cope that women require from healthcare professionals is potentially lacking.

9.5 Relevance to Nursing Practice and Patient Care

Phenomenology is a philosophy that attempts to give meaning to human experience. Uncovering the essence of everyday experience can be used to gain a deeper understanding of our experiences in the world and the phenomenological description developed from the narrative of these results can be used to ‘paint a picture’ of what it was like for women to have this experience which can be used to inform other women who are diagnosed with endometrial cancer. Understanding the experience and feelings of other women can help to reinforce that ‘you are not alone’ and reduce feelings of isolation.

However, taking the narrative and developing recommendations for practitioners has been argued as the value of phenomenology in nursing research (Crotty 1996). Using the study findings, synthesis of the literature and implications for practice, I will go on to suggest recommendations for clinical practice and patient care.

9.5.1 Recognising the Significance of a Cancer Diagnosis

Women diagnosed with endometrial cancer are primarily managed in non-specialist units. As part of the rapid assessment pathway, developed to manage women with vaginal bleeding after the menopause, women may find themselves on what was described in this study as a ‘conveyor belt’. During the maximum 62 days from referral into the rapid diagnostic service to having surgery, women with endometrial cancer or high-grade premalignant conditions are required to redefine
themselves as being-in-the world as an ill person with a potentially life threatening disease.

The structure of gynaecological cancer services in England has placed women with endometrial cancer outside of specialist services (National Cancer Action Team 2008) because of the 'simplicity' with which the disease can be surgically managed. This study, however, has highlighted the significant effect of a cancer diagnosis on these women with endometrial cancer and suggests that this should be recognised by professionals and service providers when considering what women need to be adequately supported through this treatment pathway.

The psychological needs of all other women with gynaecological cancers have been addressed by providing care in specialist units, which are required to formally recognise the psychological needs of the individual with cancer. This study has focused on the effects of the disease from the perspective of the patient and it has uncovered a potential area of inequality within the system for treating women with gynaecological cancer, which could be addressed by Cancer Networks and those commissioning cancer services. Ensuring that women with endometrial cancer have access to the same level of services that other cancer patients are entitled to should be a priority to reducing inequality and providing a high quality service for all.

As part of the survivorship agenda (Chapter 8), specialist nurses should also consider the needs of women with endometrial cancer within the Cancer Network who have not been treated at the cancer centre, ensuring that they are represented in initiatives developed to increase support for cancer patients who have completed their treatment. This is especially important in endometrial cancer where there are no recognised national support groups dedicated to these women.
9.5.2 Acknowledge the Role of the Surgeon

This study suggested that the primary concern for these women with endometrial cancer was to be cured of their disease and that this was possible, even probable, with surgery. Currently surgery can only be performed by surgeons (or robots operated by surgeons) and the surgeons in this study were seen as highly specialised individuals. The findings also revealed that the women in this study found themselves in a state of anxiety induced by fear, uncertainty and the loss of control associated with having cancer. Placing trust in the surgeon was seen as a means to achieve a cure and remove a significant amount of the anxiety by removing uncertainty.

Acknowledging the role of the surgeon in reducing anxiety by embodying specialist knowledge and expert skills is a potential step to providing appropriate support to women with endometrial cancer. Accepting that the surgical treatment of the disease may not be an area in which the patient feels she can exercise control but recognising that control can be perceived by choosing to allow the surgeon to make decisions, is a possible tool in reducing anxiety. By recognising this, nurses have the potential to concentrate on other areas of decision making that are achievable, to enhance empowerment and ensure that the team does not provide conflicting advice or information that undermines trust in the surgeon.

9.5.3 Provide Tailored Information on What to Expect

The information agenda in cancer has developed to the point of providing complex information with which cancer patients are expected to feel enabled to contribute to complex decision making about care. However, this study suggested that, for these women undergoing laparoscopic surgery for endometrial cancer, decision making was not the aim of information. What was perceived as missing,
was information about what would be done, what to expect and how to cope given their own circumstances.

To develop this in practice would mean tailoring information to the specific disease type, the specific operation, the specific department and the specific surgeon, in the context of the individual circumstances of the patient. The aim of this information would be to introduce a sense of familiarity in an unfamiliar situation and ensure that the patient was not faced with events that they had not been informed of. This requires time and the consideration of an individual consultation aimed at identifying personal needs. Part of the role of a specialist cancer nurse is to assess individual patients and provide information suitable to needs but much of the available information readily used in oncology practice, does not cover what participants in this study identified as being required and women in diagnostic units may not even have access to a specialist cancer nurse.

Providing this type of information and how a patient has access to it could be considered by specialist teams and diagnostic services. Consideration should also be given to the role of the surgeon in developing information consistent with what is being communicated in the clinical consultation.

9.5.4 Increase Access to Laparoscopic Surgery

The findings of this study concur with reports in the literature regarding a rapid postoperative recovery time for women who undergo laparoscopic surgery for endometrial cancer and illustrates the impact of this in the context of patients' lives. Unless a woman is referred to a laparoscopic surgeon, she may not be aware of the potential to have her surgery performed laparoscopically and she may be unlikely to seek information elsewhere if the surgeon recommends a treatment pathway, given the anxiety associated with a cancer diagnosis and rapid need for treatment.
Following publication of the results of the GOG LAP2 study, it is difficult to argue that women should not be made aware of, and offered access to, this treatment as a viable alternative to open surgery. Laparoscopic surgery has the potential to deliver to patients more control over their own bodies and this should arguably be the aim of medicine and healthcare services, especially for an aging population where self-care and independence may be more finely balanced. Increasing awareness of the availability of this type of surgery amongst women would enable them to seek out services that offer access to a laparoscopic surgeon.

Although there has been an increase in the number of surgeons offering women this type of surgery, there remains a considerable number of gynaecologists in diagnostic units and gynaecological cancer surgeons in cancer centres who do not perform laparoscopic surgery. As a result, up to 93% of women have open surgery as recommended by their surgeon, as discussed in Chapter 3.

Therefore, Cancer Networks should consider the potential inequalities in the services provided to women with endometrial cancer in their locality and the options available for women within the Network and in other Networks where there is access to a laparoscopic surgeon. It may also be possible for Networks to consider ways of informing women about potential treatment choices before referral to a surgeon. General Practitioners could be made aware of this treatment as a viable option for women with suspected endometrial cancer and ensure referral to a cancer diagnostic unit or centre which offers access to a laparoscopic surgeon.

When commissioning gynaecological cancer services Commissioners can ensure that the presence of a laparoscopic surgeon in a gynaecological cancer diagnostic unit or centre is part of the definition of a high quality gynaecological cancer service. This may mean that in some Networks more women would need to
be referred to a cancer centre for their endometrial cancer surgery and redefining the local pathway to incorporate all women with gynaecological cancer in the cancer centre.

Failure to address these issues potentially perpetuates an inequality that can be inherent in a system by which the chosen few continue to have access to a service denied to others because of a potential lack of knowledge regarding its existence, or unavailable referral pathways.

9.6 Strengths and Limitations of the Study

Laparoscopic surgery is a new surgical technique which has not been studied from the patient perspective. This study introduces the patient voice into the debate around laparoscopic surgery in endometrial cancer. The use of phenomenology keeps the patient voice central to the research in the way that it is structured, analysed, presented and confirmed with the participants. The strength of phenomenology is in allowing the phenomenon to speak for itself.

The limitations of the study primarily concern what has not been studied. The women chosen to participate had all undergone the procedure which had been successful in the treatment of early endometrial cancer. Part of their interpretations would be based upon their positive outcome and this would potentially be interwoven into their experience. However, it did not take into account the experiences of women who did not have a successful outcome or those who did not choose to trust the laparoscopic surgeon.

For the women in this study, the positive outcome potentially reinforced the appropriateness of their decision to trust the surgeon and transfer responsibility to his care. This could explain the relative simplicity with which these women found the
decision making process in retrospect, that is, in their retrospective interpretation of the experience. However, as discussed, the process of trusting the surgeon reduced complexity and uncertainty in a life threatening situation, which may also have contributed to the way in which these women expressed the straightforward nature of the experience of deciding to have the surgery. As one participant said, 'all I wanted to do was get rid of it' (1005:s239).

There was also the potential for participants to want to please surgeon through the researcher. They had been approached to participate in the study by the surgeon, as required by the Local Research Ethics Committee, and participation may have been perceived as a way of repaying the surgeon, potentially exaggerating the role of the surgeon and making any criticism of care less likely. However, the purpose of phenomenology is to strip away the layers of what is being said and uncover what is hidden. The use of a Heideggerian methodology also allowed me to participate in the research and interact with the participant as a nurse researcher with a shared understanding of aspects of the experience, able to react to responses to explore hidden meaning and clarify interpretation.

Nonetheless, it was beyond the scope of this study to explore more deeply some of the issues raised, such as, the experience of having cancer, except in acknowledging its profound effect on the experience of the surgery; or the concepts associated with the expressions of loss (loss of life, loss of independence, loss of normality, loss of uterus), except in recognition of the way in which this was minimised because of the ability of this type of surgery to internalise that loss and not make it visible to others.

It was also not possible to explore differences which may occur because of ethnicity and culture. Although Heidegger (1962) considers all humans to embody
how to be, this study was framed in a Western concept of medicine and Western values. The women were not chosen from a specific cultural or ethnic group and no attempt was made to consider the cultural dimensions of the experience. Despite the women in the study coming from a variety of ethnic backgrounds (White Irish, White British, Black Caribbean, Asian Indian), they were all able to communicate effectively in English, as required by the research methodology, and had been in the UK for most of their lives. It is possible that themes such as independence would differ within a different, less individualistic cultural context as would the transfer of responsibility to the surgeon, if this were already a more accepted cultural norm.

The timing of the study was also considered to have the potential to affect the study with a difference between those who are living an experience and those who have lived the experience. In phenomenology, it has been argued that it is the retrospective reflection of the experience which is of significance (van Manen 1990). However, there is less guidance on how long since an experience the meaning can be uncovered and to what extent time and memory change that experience. However, our lives are made up from all our experiences (Smythe et al., 2008) and stripping away the ‘taken for granted’ should allow for the development of a sense of what endures or what is ever present, regardless of time.

This was also a relatively small study involving only 14 women with an experience situated in the context of two major cancer centres in the South of England. It was not anticipated that a large number of participants would be required to reach the point at which a phenomenological description of the essence of the experience would emerge but the richness of the data demonstrated in the presentation of the findings, showed the strength of phenomenology in being able to uncover the meaning of the experience as interpreted by women who had
undergone the procedure. Small sample sizes in phenomenology have arguably been considered their strengths in allowing the researcher to explore the phenomenon by going deeper into the meaning (Sandelowski 1995), stripping away the 'everyday' to reveal the phenomenon hidden beneath (Heidegger 1962). Given the small sample size and the limited context in which the study was carried out, it would not be possible to generalise the findings to the whole population or those in other settings, in the way that is proposed using positivist research methods, as discussed in Chapter 4. Although it was not the intention of this study to be able to generalise in the positivist tradition, it is hoped that others can recognise the description of phenomenology. However, this study remains a single interpretation of which there may be many. Every attempt was made to make the findings as robust as possible but the very nature of phenomenology is to recognise the unique way in which we interact with the world. The stories the women told were used to create something with the potential to be meaningful and useful for other patients, healthcare professionals and service providers. However, 'a phenomenological description is always one interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially richer or deeper description' (Van Manen 1990:31).

9.7 Areas for Further Research
This study used an interpretive inductive methodology in order to generate an understanding of the experience of laparoscopic surgery for endometrial cancer. It is possible to test the findings of this study for generalisability by using deductive methods. The findings can also be used to develop research questions in laparoscopic surgery which may have more meaning for the women who undergo the procedure.
The recommendations made on the basis of the findings are suggested interventions which could be implemented within the framework of research or evaluation. For example, an intervention to increase awareness of laparoscopic surgery in a Network could be subject to an evaluation or research project.

9.8 Applicability in Other Areas of Practice

Although this study was concerned with endometrial cancer, the interaction between surgeon and patient may apply in other surgical consultations where a ‘leap of trust’ is required to undergo the procedure.

Endometrial cancer is seen as highly curable and because of this the psychological impact of the disease has often been ignored. This may also apply in other cancers where the cure rates are high, or possibly in premalignant conditions where patients enter a cancer pathway.

Laparoscopic surgery is carried out in other specialities and the findings of this study may be applicable to other specialities using laparoscopic surgery.

The findings in relation to endometrial cancer, and possibly the surgeon, are potentially applicable to both open and laparoscopic surgery.

9.9 Dissemination of Findings

The purpose of research is to generate knowledge but in order for that knowledge to be useful it must be communicated to those who would benefit from the findings. The ultimate goal of healthcare research is to inform practice. This study has implications for patients, the public, nursing, medicine and also managers, commissioners of healthcare services and policy makers. Consideration has been given to the study findings and the benefits for women with endometrial cancer, together with other areas of practice. Key stakeholders have been identified and the
plan for dissemination of the study findings reflects the diversity of the groups needed to influence change and the differing mediums through which they may be approached. This includes communicating with the participants of the study in the form of a formal Participant Letter of Thanks (see Appendix 11). A dissemination plan has been developed using the framework of goal, audience, medium, execution and evaluation and can be found in Appendix 12.

9.10 In Conclusion

This study has contributed to original knowledge and understanding by introducing the patient perspective to the literature on laparoscopic surgery for endometrial cancer. The findings of the study have produced a phenomenological description of the experience and highlighted the inequality in care delivery for women with early endometrial cancer. Recommendations made from the findings have the potential to lead to improvements in care and services which are patient focused.

This project began with my initial thoughts about why women who were offered laparoscopic surgery in the treatment of their endometrial cancer were keen to have an essentially experimental procedure to treat their disease. What I have learnt is that the answer is encased in a complex phenomenon which has been broken down through the research process, to develop an understanding that is underpinned by a rigorous framework.


Wang P.H., Yen M.S., Yuan C.C., Chao K.C., Ng H.T., Lee W.L. & Chao H.T. (1997) Port site metastasis after laparoscopically assisted vaginal


Appendix 1. Ethics Approval

London - Surrey Borders Research Ethics Committee
St Georges University of London
South London REC Office 1
1st Floor, Jenner Wing
Tooting, London
SW17 0RE
Telephone: 020 8725 0262
Facsimile: 020 8725 1897
04 July 2007

Mr xxxxx
Consultant Gynaecologist
xxxxxx

Dear xxx

Full title of study: Women's experience of laparoscopic surgery in endometrial cancer: a phenomenological study
REC reference number: 07/Q0806/52

Thank you for your letter of 26 June 2007, responding to the Committee's request for further information on the above research.

The further information was considered by the Committee Co-ordinator.

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.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

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:
R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.


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.

Feedback on the application process

Now that you have completed the application process you are invited to give your view of the service you received from the National Research Ethics Service. If you wish to make your views known please use the feedback form available on the NRES website at:

https://www.nresform.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx

We value your views and comments and will use them to inform the operational process and further improve our service.

07/Q0806/52 Please quote this number on all correspondence
With the Committee's best wishes for the success of this project

Yours sincerely

Mrs xxxx
Committee Co-ordinator

Email: xxxx@stgeorges.nhs.uk

Enclosures: Standard approval conditions

Copy to: Professor xxxx,
Appendix 2. Patient Information Sheet

To be printed on hospital headed paper

Participant Information Sheet

(22nd May 2007, Version 1)

Women's Experience of Laparoscopic Surgery in Endometrial Cancer

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. Talk to others about the study if you wish.

This study aims to explore the experience of women who have undergone laparoscopic surgery for endometrial cancer. You have been chosen because your name was given to the researcher as someone who has undergone this type of treatment in the past year.

Why is this study being carried out?

Laparoscopic surgery for endometrial cancer is a relatively new technique. Now that research has established the safety of this type of surgery, it is being offered to women in the management of their cancer. However, there have been no studies looking at what the experience means to the women who have undergone the procedure. It is hoped that by exploring the issues, as perceived by the women themselves, we will be able to offer more detailed information to women in the future. It is hoped that this information would help other women to make a more informed choice and be better prepared for the surgery. It may also help in the planning and delivery of services for women in the future.

What will happen if I decide to participate?

If you decide to participate in this study you will be contacted by the researcher to arrange a meeting at your convenience. This could be in the hospital or in your own home if you would prefer. This meeting will last for up to an hour, during which the researcher will ask you some general background questions and then you will be asked to describe your experience of laparoscopic surgery. The meeting will be tape recorded and the researcher will take some written notes. The tape recording will be transcribed to get a written copy of the interview word for word. This will be analysed for content and meaning. No information that identifies you will be included in any written copy. Your name, and the name of others that you may mention, will be replaced by a code. You will remain free to stop the interview at any point, or have any information removed from the tape or transcript should you so wish. The researcher may contact you for a second interview. You will be contacted to verify the contents of your interview and the researcher's interpretation. You may have a copy of your results at the end of the study if you would like them.
Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and 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 you receive.

Are there any risks to my taking part?
You may find the time involved in the interview an inconvenience. You may feel uncomfortable discussing your feelings and topics of a sensitive nature. It is possible that you will find it upsetting to reflect on your cancer and treatment. If you feel the need to talk to someone after the interview you can contact:

xxxx Clinical Nurse Specialist on xxxxx

What are the benefits to my taking part?
It is possible that you will gain some benefit from reflecting on your experience. You may find it helpful to have the opportunity to talk to an interested nurse. You may also feel some satisfaction to have participated in the study which aims to help women in the future and to improve services.

Will my taking part in the study be kept confidential?
Yes. All the information about your participation in this study will be kept confidential. Tapes will be stored until the end of the study and then destroyed. In the unlikely event that you discuss information that would lead to harming yourself or others, we will maintain confidentiality only as allowable by law.

What if something goes wrong?
In the unlikely event that you are harmed as a result of participation in the study due to negligence, then you may have grounds for legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of this study, the usual National Health Service complaints mechanisms are available to you. Your hospital continues to have a duty of care to you as a patient being treated within the hospital whether in a trial or not.

Contact Details:
If you would like further information regarding this study please contact:
Cathy Hughes
Xxxxx or xxxxx (24hr answerphone)

If you are unhappy with any part of this study and wish to speak to someone involved in the study at a supervisory level please contact:
xxxxx or xxxxx
Nurse Consultant Senior Research Fellow
xxxxx xxxxx

If you wish to speak to someone independent of the study:
Xxxxxx or PALS
Clinical Nurse Specialist Patient Advisory and Liaison Service
Xxxxxxxx xxxxx

What will happen to the results of the research study?
You will be given the opportunity to review the results of your own interview. The final project will be submitted for assessment for the qualification of Doctorate in Clinical Research. If successful this thesis will be held in the Library at the University of Surrey at Guildford. It is anticipated that this study will result in the writing of a research paper for publication in a Nursing journal. At no point will your identity be discussed.

Who is organising and funding the research?
This is a small scale study and no external funding has been applied for. No member of the research team will directly benefit financially from the study.

Who has reviewed the study?
This study has been registered nationally with COREC (Co-ordinating Research Ethics Committee) and has been reviewed and approved by the London-Surrey Borders Research Ethics Committee.

I would like to thank you for your consideration of participation in this study.
Appendix 3. Consent Form

To be printed on hospital headed paper

Consent Form
(22nd May 2007, Version 1)

Women's Experience of Laparoscopic Surgery in Endometrial Cancer

1. I confirm that I have read and understand the information sheet (22nd May 2007, version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by the researcher and her supervisors. I give permission for the researcher to have access to my medical records.

4. I agree to my GP being informed of my participation in the study.

5. I agree to take part in the above study.

Name of Patient Date Signature

Researcher Date Signature

Witness Date Signature

1 copy for patient; 1 copy for research file; 1 copy (original) for medical notes
Appendix 4. Samples of Patient Transcription Data

Participant 1001

R: you had laparoscopic surgery for an endometrial cancer, I wonder if you could just tell me about the experience

P: from the time I go in hospital or from the diagnosis?

R: it is up to you, whatever you think is, is important really

P: well I think the most important part of it was that, that I saw (named surgeon) and to me once I'd met (named surgeon) and he diagnosed that it was sinister, I just had so much faith in him that it, I wasn't bothered or anything, I just took it that everything would be alright and I think that I would have been absolutely astounded if it wasn't but um I was fortunate because I went into hospital on the date that I was given. I was really very fortunate to have a room with a shower and toilet in it because with the enemas and everything else they give you to clear your insides out, I don't think that I would have made it to the.....general toilets as such (R: yeah) and that to me was so important and everything was on time in the morning um the anaesthetist came in, (named surgeon) came in with his team, uh the anaesthetist came in, explained and there again I was fortunate( identifiable information removed). (R: right) (slight laugh) of course another (R: yeah, yeah) tick, really, in the box...um and then after the operation everything was fine, I didn't, obviously sore and uncomfortable to a certain extent, everything was fine until that night and the night nurses came in, um bank nurses I think they call them, and I felt very isolated because they were not as the day team. Part of it could have been it was night and I was coming round from the op (R: yeah) but when I called them because, oh no they came in to me, because I had to be monitored very regularly and one of the nurses said to me to sit up and I'd been told to go on my side but she wo... she just pulled me up (R: right, yeah) and that caused me a lot of problems coz I, after I was um, after I came out of hospital I had an infection there because the stitches had pulled (R: right OK) but that was not the operation but that was afterwards (R: yep) the care afterwards as such but I er, I was out of the hospital....I went in Tuesday afternoon and waited for a little while for a bed, got the bed, had the op on Wednesday and I came home Friday visiting time (R: right) and then went over to the GP to care and...no...everything was fine with me

R: and do, were you pleased to be going out that early or were you

P: no I was pleased because I knew that my family were around me and my husband's here and I think I had had quite a run up before I saw (named surgeon), um, not knowing what it was and being under the GP, that all the pressure of that. I was so relieved to go in hospital and have it done, that to me it was...u...it was nothing, you know, I just... and as I say, um, everything went well, it was just the unfortunate part, I think it took a month or so for the infection to go but it kept coming back...it was in the, one of the incisions (R: um) but other than that it would have been fine..
Participant 1007

P: And when I see these little small settees and 2 armchairs. I had to have that chair because it’s 18" or what d’you call it? The they came round to assess me and I, they said you'll need your toilet 18" and the chair (R: was that was that a while ago or was that after this operation?) Oh no, no, that was before (R: right).

R: And did you get any help after this operation, did any OTs or physios or anything (P: No, no) you were quite well when you left hospital?

P: Yes, just this tiredness. I hope I’m not going to stay like it but they say oh, it’s old age. But you see my sister, I’m (identifiable) this week, my sister’s (birthday) yesterday (R: right) and I’ve got another sister who will be (identifiable) this year and my brother died with had bone cancer and now, they said: has anybody in the family had cancer? I said: no. My husband had it but then he’s not my blood (R: no) but now my sister’s in a er hospital in (named hospital) and she had a terrible pain in this arm and they said she'd broken her arm, but when she had it x-rayed they said it’s, um, cancer and it’s a secondary so the cancer must be coming from somewhere else. And now she says she found a, I thought she said she’d found a lump in her tummy, but she rang just before you came um because the kids were making a noise I couldn't really hear, but (name) said she said, I thought she said it was a, oh, what do you get sometimes um? Oh I'm so, I can't remember the names of things. She said: no, she said it was in, in her bottom or something, but she told me she'd got a, she got a lump there, so we don't know. And then they, they said, the doctor came and sat with her, held her hand and told her it was cancer. Then the nurses came up to her afterwards and said oh that was, sorry they got muddled up, that was someone else's, er, but they should never have told her, should they, if that was the case. (R: No.) But so, and she's one of those people who doesn't talk. Now when I was in hospital the nurses and the doctors were ever so chatty to you, you know (R: yeah) but she doesn’t talk, she says: yes, and um I just can’t make it out what's wrong with her really (R: yeah) but I'm worried about her, she’s the youngest one.

R: And how did your sisters find, you know, about your cancer and your (P: Pardon?) How, how do your sisters feel about you?

P: Oh they were very upset (R: having your cancer and) they were upset, my sister she keeps, kept ringing me every day and they all did (R: yeah) and they couldn’t understand me because I wasn't worried about it. (R: no. Why weren't you worried about it?) No, I’ve always dreaded the word cancer (R: yeah) I think everybody does really, but when they actually said I’d got it I was quite, they couldn’t understand it because I wasn’t in the least worried, but I’ve been more worried since, thinking it might come back (R: right) than, it was only because it said it in this, the doctor, my own doctor said it’s a very, it’s very, very rare that it will come back (coughs) but that's it (R: yeah).

R: And no-one can ever tell you it won't come back, that's the problem

P: No. They don't know, do they. yeah, yeah. It was really, really nice when they told me about it. He, he said: oh you've got a nice, um not caring, a nice family, you know, he was chatting to them and telling them, you know. I didn't want to know
what they did (R: right) he said: I'm afraid we're obliged to tell you what were going
to do. I'd rather shut my eyes and... 

Participant 1010

R: And did you tell all your friends and family why you were having a
hysterectomy or that you were having one?

P: I told my closest friend and then I wrote a letter to another friend at
(identifiable) because I couldn't tell her over the phone, I knew that I would cave in.
Because apparently the hardest thing to say, is to tell someone, I've got it, um, I was
okay and then I had to tell them because I'm treasurer of my (identifiable) and I, I
hadn't told anybody down there about the bleeding or anything but I just sort of
phoned the president and said: I've got something to tell you and I said I've got a,
well I had to tell them because I was going in for the biopsy, because he was coming
round to look after my (animals) and so I had to tell, tell him and then when I got the
results I just said to him I, I'm going in, but um I said to him, but you know I said: I'm
not even worried about this I said, that's the doctors' problem not mine.

Because I never had problems, I always have challenges you see (R: yeah) I
just sort of that's my attitude and then um (named surgeon) he said to me that I was,
they was going to go for keyhole but he said there's always a chance that you may
not be able to have keyhole and that was, I thought, oh God, I hope I do have
keyhole and then when I come round, they were all saying to me: oh, you've had
keyhole surgery!

I said: oh thank God for that! I just sort of wanted to sleep again then. But yeah,
that was, not: hello (name), are you okay? They just said: oh your neighbours are all
excited as well, and that was quite funny really. (R: yeah) But it was such a fantastic
team there. I, I'd recommend anybody that's got any trouble in that area, go there
and nowhere else.

R: And and what about pain, when you woke up?

P: No, no. I was on the drip and I was on an insulin – that caused me more
trouble the insulin drip, it kept pulling on my hand and that was driving me round the
twist. The only pain, the wadding. (R: right) I'd been told about the packing and I
thought the girl in the pet shop was having me on and she said: no; I said: you're
having me on, because you know, you know I don't like pain, and she said: no
(name), she said, and her mum said to her: why the hell did you tell (name)? She
says, she'll worry about it, she said: she needs to know about it.

And it was awful, when they pulled that wadding out. (R: yeah) I wish they'd told
me, because I still thought she was having me on and I wish, that's the only thing I
wish they'd told me about but about the wadding, because then I could have took
some Vaseline to put on myself, because when I tried to go to the toilet it was sheer
agony (R: yeah).

And I remember going to the nurse and I said: can you get me something from
pharmacy, er like Vaseline, something to stop this stinging, and she said: no, it will
wear off, I said: it will not, I said: please, and she they got me some oily stuff which
helped but, I was glad to get home to get put the Vaseline, because when I tried to go to the toilet it was sheer
agony (R: yeah). I had to have that. I did swear when they pulled I swore when they pulled the padding out, but not at them, I
was just going ahhhhhh like that, er, oh that was that was the worst bit, the padding.
R: And when did that come out?

P: I think, I think it came out the next day (R: right). Yeah, I was uncomfortable sitting on it as well, because I thought oh, but I didn’t know it was gonna because they do it so quick, which is the best way to do it really (R: yeah) rather than do it slowly, they just whaaa, God did I...that was the worst. There was no other pain (laughter) and you think you’d get pain when they...
## Appendix 5. Examples of Formulated Meaning

<table>
<thead>
<tr>
<th>Participant</th>
<th>Verbatim statements</th>
<th>Significant statements</th>
<th>Formulated meaning (creative insight)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1001</td>
<td>thinking about what I had to do</td>
<td>having to think about innate functions</td>
<td>an awareness of the body</td>
</tr>
<tr>
<td>1001</td>
<td>I went on to sanitary towels.</td>
<td>the use of sanitary protection</td>
<td>inconvenience of bleeding again</td>
</tr>
<tr>
<td>1001</td>
<td>I just said I had a hysterectomy and that, left it at that, I was selective in who I told.</td>
<td>not telling friends and family about the cancer</td>
<td>controlling who to tell</td>
</tr>
<tr>
<td>1001</td>
<td>just like little blobs.</td>
<td>small scars</td>
<td>little to show for having had the surgery</td>
</tr>
<tr>
<td>1001</td>
<td>I don’t think at my age</td>
<td>older women do not need to consider cosmesis</td>
<td>is not a concern for</td>
</tr>
<tr>
<td>1001</td>
<td>difficult not doing anything</td>
<td>found it hard to rest</td>
<td>disruption of normal life</td>
</tr>
<tr>
<td>1002</td>
<td>the food was terrible</td>
<td>the food was not good</td>
<td>not eating the hospital food</td>
</tr>
<tr>
<td>1002</td>
<td>the healthy can be ill</td>
<td>the healthy can be ill</td>
<td>not being aware or in control of</td>
</tr>
<tr>
<td>1002</td>
<td>because I know the longer you stay in hospital the more relationships with other people you know, how you broke this to someone.</td>
<td>longer hospital stays result in more problems</td>
<td>hospitals are risky places</td>
</tr>
<tr>
<td>1003</td>
<td>I must have had some kind of MRSA</td>
<td>infection in cannulae site</td>
<td>hospitals are risky places</td>
</tr>
<tr>
<td>1003</td>
<td>I was actually sort of sitting on the bed with my legs stretched out and that seemed to be the most comfortable, left side of my abdomen was somewhat sore.</td>
<td>discomfort in position</td>
<td>being affected by discomfort</td>
</tr>
<tr>
<td>1003</td>
<td>because I don’t feel I am still terribly fast when I’m walking, this need to take things easy, still an awful lot you have to be careful with not up to full activity</td>
<td>disruption of normal life</td>
<td></td>
</tr>
<tr>
<td>1003</td>
<td>smaller incisions, little ones made the constipation really bad, definitely a constipation problem I haven’t I’m not going to end up with a great big scar.</td>
<td>small incisions problem with constipation</td>
<td>little to show for having had the surgery</td>
</tr>
<tr>
<td>1004</td>
<td>More than the operation. (R: right. Routine infections or new infections, or both?) Well, the superbugs (R: yeah) because we all know what can happen there fear of hospital aquired infections</td>
<td>hospitals are risky places</td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>Participant</td>
<td>Verbatim statements</td>
<td>B</td>
</tr>
<tr>
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</tr>
<tr>
<td>1004 um in a hot room</td>
<td>I can’t bear being on wards with other people, especially when you don’t have anybody around you sleeping and snoring and and creating and and I don’t like being because you’ve got less chance of infection and catching anything else, haven’t you really, you won’t get any MRSA</td>
<td>not wanting to be in an open ward</td>
<td>less chance of infection</td>
</tr>
<tr>
<td>MRSA</td>
<td>that’s it but and you’ve got nothing afterwards, nothing to, no stitching or no, that’s all you’ve got, of course you’ve got no drains or anything have you, you’ve just got the catheter in that was all</td>
<td>little to show for having had the surgery</td>
<td>little to show for having had the surgery</td>
</tr>
<tr>
<td>1005</td>
<td>I felt sick but that was all</td>
<td>feeling nauseous</td>
<td>hard to believe the surgery has been performed</td>
</tr>
<tr>
<td>1005</td>
<td>I find it hard to believe I’ve had that done now, unless I look in the mirror and, you know, I see it I think oh God, you know, cover it up and remind me about it again in a few months when it’s time to go so you’ve got no, you can just get on with it I didn’t sleep that night, that machine by your by your head going: flick whirrr, flick, flick, whirrr, flick</td>
<td>looking in the mirror is the only reminder of the surgery</td>
<td>the scars are a reminder of the surgery/cancer</td>
</tr>
<tr>
<td>1006</td>
<td>also it’s nice to get back into the real world, you begin to forget there’s an outside world there</td>
<td>getting back to the real world</td>
<td>getting back to normal life</td>
</tr>
<tr>
<td>1006</td>
<td>I stopped taking them after the fourth night and I didn’t need them, you know, I mean there was transitory pain as you can possibly not taking pain killers for long</td>
<td>not much pain</td>
<td></td>
</tr>
</tbody>
</table>

289
<table>
<thead>
<tr>
<th>Participant</th>
<th>Verbatim statements</th>
<th>Significant statements</th>
<th>Formulated meaning (creative insight)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1006</td>
<td>and so I didn't tell people many people that, well I didn't tell anyone that I didn't trust just to keep it to themselves, because I thought, I don't know whether I want anyone to know or I don't want anyone to know, some I told it was cancer.</td>
<td>not telling friends and family about the cancer</td>
<td>controlling who to tell</td>
</tr>
<tr>
<td>1006</td>
<td>all healed up very quickly</td>
<td>rapid healing</td>
<td>little to show for having had the surgery</td>
</tr>
<tr>
<td>1006</td>
<td>not that it matters at my age</td>
<td>not mattering for older women</td>
<td>cosmetics is not a concern for older women</td>
</tr>
<tr>
<td>1006</td>
<td>I thought oh my stomach...and that evening I sat in that chair and all of a sudden I got this warm feeling and all this brown, dark brown stuff came running down, blood came</td>
<td>acute and dramatic symptoms</td>
<td>severe symptoms</td>
</tr>
<tr>
<td>1007</td>
<td>had never been in hospital before and I was absolutely petrified I can't wear the liner and this and that and got blood all the time</td>
<td>being frightened having never been in hospital before using sanitary protection again</td>
<td>hospitals are frightening inconvenience of bleeding again</td>
</tr>
<tr>
<td>1008</td>
<td>I'm confident only when I'm going from bed and loo, and after that I came down and once I came down and I was able to walk, She stayed upstairs basically then everybody's looking at you differently and give you more advice, the people with a little knowledge then I tell if it is still there, I don't know she hasn't any scars they are expecting her to be very much, you know, you know, she come back, she come back, everybody say she come home, she come home, if you were ill you should have been left a lot longer, when they look at my face they say 'you look OK and I say 'yes' but only I know the pain</td>
<td>being seen differently if you have cancer not being aware if the cancer is still there not being aware or in control of what is going on in the body</td>
<td>altered perception of self little to show for having had the surgery</td>
</tr>
<tr>
<td>1008</td>
<td>without scars and being home so soon others feel you are not really ill</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1008</td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Participant</td>
<td>Verbatim statements</td>
<td>Significant statements</td>
<td>Formulated meaning (creative insight)</td>
</tr>
<tr>
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<td>------------------------</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td>1010</td>
<td>I come down? I went: you, she said: I can't believe it! She said I cannot believe that you have just had a major, the paper shop to (name) on the Sunday he said what are you doing out?, (name) couldn't have had that because my daughter was flat on her back and she couldn't have had a proper hysterectomy and I said I'll bring the letter to show them, if they want, yea</td>
<td>others not believing the extent of surgery</td>
<td>little to show for having had the surgery</td>
</tr>
<tr>
<td>1011</td>
<td>I had a period but it would not stop and he gave me the Danazol and I was just pumping blood, I became really badly anaemic</td>
<td>the severity of the symptoms</td>
<td>severe symptoms</td>
</tr>
<tr>
<td>1011</td>
<td>I got a cab, because you are not allowed to drive, (named surgeon) said to keep off public transport and then the January I had to go back full time and I found that quite tough</td>
<td>not being able to drive or use public transport</td>
<td>disruption of normal life</td>
</tr>
<tr>
<td>1011</td>
<td>I didn't tell my mother, I still haven't told my mother</td>
<td>not telling friends and family about the cancer</td>
<td>not easy to get back to work</td>
</tr>
<tr>
<td>1011</td>
<td>I haven't even had to take pain killers.</td>
<td>no need for pain killers on discharge</td>
<td>controlling who to tell</td>
</tr>
<tr>
<td>1012</td>
<td>after anything like that it takes you 1012 days to go properly and things they said it would be quicker but I didn't think it would be that quick, told them at the clubs then you won't see me for … what happened I wouldn't say you were, discomfort but not pain</td>
<td>bowel being disrupted by the surgery</td>
<td>not much pain</td>
</tr>
<tr>
<td>1012</td>
<td>I've told my immediate family and um, very close friends (R: okay) yeah, that's all, she actually hadn't told anyone in work. She 'd told them she 'd had a hysterectomy but</td>
<td>being surprised at how well I was post op</td>
<td>disruption of bodily functions</td>
</tr>
<tr>
<td>1013</td>
<td>5 weeks ago and um I still get tired, I've told my immediate family and um, very close friends (R: okay) yeah, that's all, she actually hadn't told anyone in work. She 'd told them she 'd had a hysterectomy but</td>
<td>just told close family the diagnosis</td>
<td>getting back to normal life</td>
</tr>
<tr>
<td>1013</td>
<td>though I ain't told my Dad, I didn't tell my Dad that I had cancer when I went back after 6 weeks I went on light duties and I didn't go back doing full time I just do a couple of hours you know</td>
<td>not told parents</td>
<td>feeling tired</td>
</tr>
<tr>
<td>1014</td>
<td>not told parents</td>
<td>controlling who to tell</td>
<td>not easy to get back to work</td>
</tr>
<tr>
<td>1014</td>
<td>went back to work on reduced duties</td>
<td></td>
<td></td>
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</tbody>
</table>
### Appendix 6. Theme: Having Cancer

<table>
<thead>
<tr>
<th>Formulated Meanings</th>
<th>Sub-theme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowing it is cancer.</td>
<td></td>
<td>A cancer diagnosis</td>
</tr>
<tr>
<td>Knowing something is wrong.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shocked by the cancer diagnosis.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer kills people.</td>
<td></td>
<td>Fear of cancer</td>
</tr>
<tr>
<td>Cancer makes other things insignificant.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denial of own fallibility.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denial of the possibility of cancer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Facing up to having cancer.</td>
<td></td>
<td></td>
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<tr>
<td>Fear of cancer.</td>
<td></td>
<td></td>
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<tr>
<td>Fear of cancer pain.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of dying in surgery.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of recurrence.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of vaginal examinations.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No choice but to have the cancer removed.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not frightened by the diagnosis of cancer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outcome is the most important thing.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speaking about it would make it real.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The cancer is something evil/sinister.</td>
<td></td>
<td></td>
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<tr>
<td>Worry about responsibility.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being positive.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being told that I am cured.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rapid treatment.</td>
<td></td>
<td>Speed of treatment</td>
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<tr>
<td>Quick admission caused confusion.</td>
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</tbody>
</table>
### Appendix 7. Theme: Information and Support

<table>
<thead>
<tr>
<th>Formulated Meanings</th>
<th>Sub-theme</th>
<th>Theme</th>
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</thead>
<tbody>
<tr>
<td>Different ways to interpret information.</td>
<td></td>
<td>Knowledge and Understanding</td>
</tr>
<tr>
<td>Difficult to use the internet for information.</td>
<td></td>
<td>Information and Support</td>
</tr>
<tr>
<td>Doctors control information.</td>
<td></td>
<td>Preconceptions</td>
</tr>
<tr>
<td>Fear of information.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting information from others.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Imagination can be worse than reality.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information can be confusing when vulnerable.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information contradictory.</td>
<td></td>
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<tr>
<td>Information needs to be positive.</td>
<td></td>
<td></td>
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<tr>
<td>Information not practical.</td>
<td></td>
<td></td>
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<tr>
<td>Low level of knowledge.</td>
<td></td>
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<tr>
<td>Making sure of understanding.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moving on from the procedure.</td>
<td></td>
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</tr>
<tr>
<td>Not being dramatic/ calm.</td>
<td></td>
<td></td>
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<tr>
<td>Not being told basic information.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeking information from the Internet.</td>
<td></td>
<td></td>
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<tr>
<td>Information helped once persuaded to read it.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The need for information.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understanding was important.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unfamiliar language is used.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wanting something tangible.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Without information- no control.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A logical sense that laparoscopic is better.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A sense of violence with open surgery.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being better than other patients.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits to other people.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer can be curable.</td>
<td></td>
<td></td>
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<tr>
<td>Experience of surgery.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hysterectomy is less common.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowing the significance of five years.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laparoscopic surgery is not like real surgery.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Making assumptions.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Notions of what laparoscopic surgery is.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Open hysterectomy is a big operation.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive experience of hysterectomy outcome.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preference for laparoscopic surgery.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prior knowledge and interest in cancer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being alone.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being in contact with other patients.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family support.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No community support.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No time to develop relationships in hospital.</td>
<td></td>
<td></td>
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<tr>
<td>Only of concern to women.</td>
<td></td>
<td></td>
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<tr>
<td>Supporting others.</td>
<td></td>
<td></td>
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</tbody>
</table>

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Appendix 8. Theme: Independence

<table>
<thead>
<tr>
<th>Formulated Meanings</th>
<th>Sub-theme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>A requirement for GP/community services.</td>
<td></td>
<td>Independence</td>
</tr>
<tr>
<td>Demonstrating high risk.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discharge poorly planned.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Embarrassed at intimate examinations.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of dependence.</td>
<td></td>
<td>Dependence</td>
</tr>
<tr>
<td>Frightened of being alone.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needing post op advice.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not being able to be home alone.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not ready to go home.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not possible to have what you want.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preference for female doctors.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unable to get community support.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being fortunate.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being lucky.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being told where to get help.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experienced nurses have a deeper level of understanding.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good nursing care.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kindness is important.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needing advice post op.</td>
<td></td>
<td>Independence</td>
</tr>
<tr>
<td>No one to contact for advice.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not enough nurses.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing care better in NHS.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor nursing care.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff friendly and professional.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Isolated.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being done to and not an equal partner.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being treated like a human being.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being vulnerable.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unable to manage independently in hospital.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being independent.</td>
<td></td>
<td>Self-reliance</td>
</tr>
<tr>
<td>Glad to be home.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No inconvenience to others.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needing to be prepared.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No need for community support.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking control of recovery.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Able to manage the stairs.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being mobile.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficult to mobilise with drips and catheter.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility was easier with laparoscopic surgery.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asserting oneself.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being an individual.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Struggle to get laparoscopic surgery.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controlling who to tell.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 9. Theme: Normality

<table>
<thead>
<tr>
<th>Formulated Meanings</th>
<th>Sub-theme</th>
<th>Theme</th>
</tr>
</thead>
</table>
| A disparity in what can be seen/felt and what can be done.  
Cosmesis not a concern for older women.  
Cosmesis not a concern.  
Not being aware/in control of what is going on in the body.  
Little to show for having had the surgery.  
Not wanting to appear ill.  
Not seeming real.  
Not wanting to be seen as you really are.  
The scars are a reminder of the surgery.  
Having five incisions.  
Altered perception of self.  
An awareness of the body.  
No longer the same as before.  
Losing confidence in self.  
No menopausal symptoms.  
The uterus representing womanhood.  
Regret at losing the uterus.  
Unexpected improvements since the operation.  
Being able to continue to work.  
Complications.  
Disruption of bodily functions.  
Disruption of normal life.  
Enjoying time off.  
Feeling tired.  
Not feeling tired.  
Getting back to normal life.  
Inconvenience of bleeding again.  
Not easy to get back to work.  
Severe symptoms.  
Taking time off that is due.  
A level of privacy.  
Being set free.  
Hospitals are frightening.  
Hospitals are risky places.  
Normality away from the hospital bed.  
Not being able to sleep.  
Not eating the hospital food.  
The staff were approachable.  
Unnecessary waiting.  
Being affected by discomfort.  
Not much pain.  
Not painful but uncomfortable.  
Pain after the operation.  | Appearance    | Normality |
| Disruption                                                                                                                                                                                                         |              |         |

### Appendix 10. Transfer of Responsibility to the Surgeon

<table>
<thead>
<tr>
<th>Formulated Meanings</th>
<th>Sub-theme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>High level of surgical expertise.</td>
<td>Faith in the surgeon</td>
<td></td>
</tr>
<tr>
<td>Disappointment at not seeing the surgeon.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Faith in the surgeon.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>God and surgeon as saviour.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minimal contact with the surgeon.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not in the best situation to meet the surgeon.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The surgeon embodies the success.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worship of the surgeon.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery not at fault for complications.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Open surgery is old fashioned/traditional.</td>
<td>Modern</td>
<td></td>
</tr>
<tr>
<td>Medicine has advanced.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The surgery is advanced.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The unit is modern.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being taken care of.</td>
<td></td>
<td>Transfer of responsibility to the Surgeon</td>
</tr>
<tr>
<td>Being the centre of attention.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Could not admit to ignoring advice/symptoms.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distrust of unit doctor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctors control information.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Faith in the team.</td>
<td></td>
<td>The passive patient</td>
</tr>
<tr>
<td>The surgeon too important to see patients.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The surgeon knows what is best.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The surgeon not getting the full picture.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfer of responsibility of care.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfer of responsibility to the doctors.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unable to make own decisions.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unable to monitor oneself.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would have done anything told to do.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doing as told.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not complaining.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blaming self for delay in diagnosis/ outcome.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking the blame for feelings and emotions.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 11. Participant Letter of Thanks

Dear

Re: Women’s Experience of Laparoscopic Surgery in Endometrial Cancer

I would like to thank you for your participation in the above study. The data collected will contribute to a better understanding of the experience of laparoscopic surgery when used in the treatment of endometrial cancer.

Please remember that any data pertaining to you, as an individual participant, will be kept confidential and any quotes used in publications will be anonymised. All the data has now been collected and analysed and we plan on sharing this information through conferences, presentations, journal articles and cancer networks.

If you are interested in receiving more information regarding the results of this study, or if you have any questions or concerns, please feel free to contact me at cathy.hughes@npsa.nhs.uk or on 0207 927 9511. In particular, if you would like a summary of the results, please let me know.

Once again I sincerely thank you for your time in participating in this study.

Yours Sincerely,

Cathy Hughes
## Appendix 12. Dissemination Plan

<table>
<thead>
<tr>
<th>Goal</th>
<th>Audience</th>
<th>Medium</th>
<th>Execution</th>
<th>Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inform Participants</td>
<td>Study Participants</td>
<td>Direct mailing</td>
<td>Letter of Thanks (Appendix 11)</td>
<td>Receipt of letter. Requests for details of study findings.</td>
</tr>
<tr>
<td>Influence NICE guidance</td>
<td>NICE technology appraisals and clinical guidance.</td>
<td>Internet.</td>
<td>Respond to NICE consultation.</td>
<td>Acknowledgement from NICE. Recognition of study findings.</td>
</tr>
<tr>
<td>Raise awareness for women</td>
<td>The general public and women who have endometrial cancer.</td>
<td>Articles in lay press, Websites, RCN (mainly women), Charities.</td>
<td>Check patient websites include details of laparoscopic option.</td>
<td>Websites amended. Details of study referenced on sites.</td>
</tr>
<tr>
<td>Influence commissioners</td>
<td>Cancer Commissioners</td>
<td>NDP</td>
<td>Lobbying groups: Charities, RCN, Westminster keynote seminars, Local MP.</td>
<td>Present at NDP. Mention at Network meetings. Discussions with nurse directors.</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------------------</td>
<td>-----</td>
<td>------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
10.1 Introduction
The overview of the integration of knowledge, research and practice represents a reflective account of how the taught elements of the doctoral programme, together with the research project, have contributed to the integration of research knowledge into my own clinical practice.

10.2 Starting Out
As a specialist nurse in cancer I had been involved in research trials, primarily multi-centre clinical trials focused on the medical treatment of cancer or cancer symptoms. Although I had conducted a research study as part of a Masters degree, I did not feel I had developed sufficient skills to set up and lead on research projects. In an attempt to gain a better understanding of research, I applied for a post at the relatively newly formed Cancer Research Network. Nurses working on clinical trials are often primarily involved in data collection and management of the research process. However, although this was a good grounding in the research process and the wider issues involved in clinical trials, it did not increase the knowledge and skills required to design and conduct a trial, nor did it equip me to influence nursing care in the design of studies.

The management of individuals in healthcare is a multi-professional dynamic process and the journey a patient takes should not be seen by professionals a series of broken steps but the continuum as it presents itself to the individual. For me nursing has two responsibilities when it comes to research: 1) to develop the profession by ensuring evidence based care is provided by nurses and 2) to ensure...
that aspects of nursing care can be used to influence patient care and treatment in a wider context. Nurses can do this by engaging in research around aspects of nursing care, engage in research about aspects of clinical treatment and use their skills to manage and recruit patients into clinical trials. This would mean nurses being involved with the development, as well as the delivery of clinical research.

Working in the clinical trials environment made me realise I lacked an understanding of a broad range of research methodologies, the language to communicate in the research environment, the confidence to assert the value of nursing in research, the ability to engage with the research community and the skills and knowledge to influence the agenda.

10.3 A Deeper Understanding of Research

The taught element of the doctorate introduced me to the complexities of research and gave me a much deeper understanding of the main research methodologies. Having already identified my lack of knowledge in research and having moved into a research focused environment, I was also learning about the set up and conduct of multi-centre clinical trials, in a newly formed national body with a remit to increase recruitment of cancer patients into trials.

Reading and assessing the appropriateness of trials and applying them in a locality and hospital structure was part of my role and the doctorate was influencing my ability to do this. The module on advanced research methods allowed me to explore a comprehensive range of research methods and to understand their use and application in practice. The statistics module broadened my understanding but made me realise how little I, and the research nurses I was managing, understood about statistics which was significantly hindering our ability to effectively read and comprehend research articles and protocols. Through discussions with the Network 301
Manager we were able to set up a workshop and programme of statistical updates for our research staff. Identifying my own needs helped me to identify the needs of the other nurses in the Network.

Having worked in cancer clinical trials on a target of entering more patients into ‘high quality’ trials defined as Randomised Controlled Trials and using questionnaire design for my Masters, I found the expansion of my knowledge of qualitative research opened up a fascinating and for me, an incredibly intuitive discipline. I also felt phenomenology as a research methodology could have a significant impact on my clinical practice. As I wrote in my reflective diary:

‘As a cancer nurse I feel I can not necessarily change the disease outcome but I can change the experience’

10.4 The Language of Research

Language is the key to communication. Understanding the way communities communicate is vital to being considered a part of that community. Nurses often lack the language to communicate within the research world and as such are removed from the conversation and are left to participate at the fringes. This inability to use the correct language often leaves others feeling that nurses do not understand, rather than just being unable to communicate. Dismissing others who are not able to communicate in the same way is a form of prejudice but it does exist and can be used to maintain exclusivity. Understanding advanced research methods as part of the doctorate, the exposure to the clinical trials environment and the extensive reading involved in the doctoral process gave me the vocabulary to be accepted by the research community and also to be able to facilitate communication between nurses and more traditional researchers. The communities of practice module helped me to understand the complexities of the development and maintenance of
communities in clinical practice and how to consider the barriers to communication as well as the potential for influence.

10.5 Confidence

Developing a deeper understanding of research and having the ability to communicate in the research community gave me the confidence to actively participate in the research agenda. Although I had always appreciated the intrinsic value of nursing in patient care, through the doctoral programme I came to realise the scale of the importance of the nursing contribution and how nurses underestimate their worth. Refocusing on the healthcare environment and seeing it in a different way was a turning point in my confidence. The things that matter to patients are the things that should matter to healthcare. An example of this can be seen in my reflective diary:

'Patients often ask me if they can talk to other women who have had the same experience – other women's experience of the surgery matters to them'

Nurses have one of the closest relationships with patients of all healthcare practitioners because of their prolonged involvement with basic human needs and activities during times of extreme vulnerability. Understanding and appreciating the contribution that nurses and nursing has to make to patient care has kept me focused and in contact with nurses via the Royal College of Nursing and my elected steering committee position on the Gynaecological Nursing Forum (which has recently become the Women's Health Forum) and my contact with the cervical cancer charity Jo's Trust.

With confidence in my ability to communicate and a belief in the importance of what I have to contribute, I have been able to focus on the content and purpose of
disseminating information through presentations and increase my participation in formal presentations.

10.6 The Ability to Engage with the Research Agenda

Doing my own research project has given me a practical understanding of the research process from the conception of the idea of the problem to be addressed or understood, through to the structure provided to protect participants in studies, through conducting a study with analysis of the data, synthesis of the results into something meaningful for others and dissemination to the wider community. I have also worked with the Medical Research Council on a project regarding individual patient meta-analysis in cervical cancer. The Service Development Project brought the role of clinical audit in the delivery of services and the conduct of research into focus for me. Understanding the interplay of research, audit, evaluation and implementation became part of my learning and development. Through this I was also able to publish an article on the evaluation of a teaching programme concerning informed consent in cancer clinical trials developed with a small group of colleagues.

10.7 The Ability to Influence

As Lead Nurse for the Research Network, I was also the National Training Link for the programme of education developed by the NCRN (National Cancer Research Network) to ensure the rapid training of this new workforce. Completing the Policy Review not only gave me an understanding of the specific policy affecting women with endometrial and gynaecological cancer, it also developed my understanding of the political process and the complex nature by which individuals and organisations can influence the political agenda. I had not realised just how powerful the individual can be in a democratic society. My Policy Review was used as the basis of a
session I gave at a training module at the NCRN on Cancer Policy and Politics and
my slides were used as the template for this session.

With this greater understanding of the political and strategic aspects of
healthcare, I stood and was elected as Chair of the Gynaecological Nursing Forum
and was able to lead the Forum at a time of major reorganisation and influence the
agenda through membership of the Forum Governance Group at the RCN.

I have also now written to my MP regarding health matters on several occasions
and realised the importance of this in UK political process, especially when your
local MP is a Health Minister. On behalf of the RCN, I have also presented to a
meeting of MP's at the Houses of Parliament regarding cervical cancer when
decisions about the HPV vaccine were being discussed at a political level.

I was given the opportunity to present my research at a research meeting of two
London cancer centres. I was the only researcher presenting a paper using an
interpretive methodology to a room of scientists and senior medical staff. The
presentation generated real interest from the surgeons who could see the value in
research to develop solutions to the problems identified by patients and an
understanding of the patient experience.

My consideration of the ways to influence others, identified in the module on
communities of practice, led me to set an appraisal objective to increase my
publications in 2008. I managed to get several update articles published to share
clinical knowledge and contributed a chapter in the Royal College of Obstetrics and
Gynaecology yearbook on multi-disciplinary care. Having managed to overcome
some of the nerves associated with presentations and realised the value of this
medium in getting the message across also led to me making a conscious decision to improve my presentation skills and number of presentations.

In the summer of 2008 I moved in to a post working at a more strategic level in healthcare and became the Cancer Lead at the National Patient Safety Agency. I have managed to use and extend all of the skills I have developed on the doctoral programme. I am involved with analysis of qualitative data, I represent cancer as a specialty at the Agency, I contribute to the understanding of nursing as it happens in practice, I contribute to making healthcare safer for cancer patients, I am involved with the dissemination of good practice, the writing of national guidance documents, the evaluation of initiatives designed to improve healthcare and the imbedding of change in complex organisations. I was also interviewed for a profile piece in the Nursing Standard about my career and development as a nurse.

10.8 Conclusion

Since entering the doctoral programme nearly five years ago, I have developed in ways that have led me to become an advanced practitioner in nursing. I have been able to develop the knowledge and skills, as well as the understanding, to confidently communicate and engage with a wide range of agendas in healthcare. I have been able to demonstrate that I am now more able to influence and lead on clinical practice and to represent nurses and nursing in the improvement of care and treatment for patients.
CHAPTER 11: RESEARCH LOG

11.1 Introduction

This research log represents a summary of the development of my research skills over nearly five years of doctoral study. Because of the nature of the methodology used in my research project I primarily kept the record of my development in the reflective diary maintained as a mechanism to demonstrate rigour and provide an audit trail. The reflective diary was supported by records of my supervision, university annual reports, ethics committee annual reports and the many topic specific note books I kept as part of the doctoral process.

11.2 Learning Needs Analysis

One of the reasons I chose to do a taught doctorate was because of the structure and support it offered in developing the skills required to complete a piece of doctoral research. The first formal assignment was to complete a learning needs analysis. Developing an understanding of my own needs on commencing the study involved an in-depth consideration of my motives for wanting to undertake the doctorate and an assessment of my strengths and weaknesses with regard to study skills, writing skills, cognitive skills, practical skills, communication skills etc. This helped me to focus on the requirements of the course and my ability to achieve and deliver.

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Understanding of the ethics process and GCP</td>
<td>• Breadth of understanding of research methodologies</td>
</tr>
<tr>
<td>• Ability to access a wide range of research material</td>
<td>• Goal setting and project management</td>
</tr>
<tr>
<td>• The ability to identify my own needs</td>
<td>• Self discipline</td>
</tr>
<tr>
<td>• Writing skills</td>
<td>• Presentation skills</td>
</tr>
<tr>
<td>• Computer skills</td>
<td>• Listening skills</td>
</tr>
<tr>
<td>• Networking</td>
<td>• Statistics</td>
</tr>
</tbody>
</table>

307
Most of my notes in the initial phase were concerned with grasping the basics of how the University worked and how I could best use the facilities, together with some evidence of developing relationships and an identity with other members of my cohort.

11.3 Key Milestones

The key events in the research process were identified as any key activity, major hurdles, major breakthroughs or other significant events impacting on the research process.

11.3.1 Topic Review

Developing the research project began early on with the requirement to produce a topic review at the end of the third month, April 2005. This topic review became the basis for my research proposal which then went on to provide the skeleton for the research project. When I applied to do the doctorate I was working as a Lead Nurse in a Cancer Research Network and my initial thoughts on a topic for study were concerns around informed consent in cancer clinical trials which was a major component of my role at the time. However, I realised this was not my main area of interest and spending four years in the study of something I was not totally committed to may prove difficult. I had maintained my clinical specialty interest by leading on the recruitment into gynaecological cancer trials and I decided to pursue my interest in laparoscopic surgery in endometrial cancer for my research topic.

11.3.2 Return to Gynaecological Oncology

Although I had access to gynaecological cancer patients as part of my clinical role in the Network, there was also pressure for me to take on more management for the Network to run efficiently. At this point I decided to return to gynaecological cancer nursing practice as a specialist nurse, I went to work in another Cancer
Network where one of the surgeons performed laparoscopic surgery and was willing to support my study. It was at this point that I commenced supervision and the process of refining my research aims and consideration of the most appropriate study design began. However, I remained focused on the summative assignments at this time.

11.3.3 Policy Analysis

The Policy Review helped me to understand the complexity of healthcare services and the underlying political drivers influencing gynaecological cancer care. I also learnt how to access political and non-clinical healthcare information.

11.3.4 Service Development Project

The service development project introduced me to clinical audit and the role of audit in healthcare. I was required to submit my request for data to the audit team with a summary of the proposed audit and how the information would be used. Part of this assignment was to present the projects to the teaching staff and my peer group. I had identified presentation skills as one of my weaknesses and this experience allowed me to present the project formally.

11.3.5 Research Design

Early supervision records show my main concerns through to May 2006 were around the Policy Review and Service Development Project. Once these were submitted and the Service Development project was presented, discussions with my main supervisor around the research methodology led to me to phenomenology and the development of the research proposal. Although my main supervisor influenced me in this decision, it was through a process of enabling me to understand what I was actually trying to achieve and gradually realise for myself that phenomenology was the best way that this could be done.
11.3.6 Ethics Submission

The study was submitted for ethical review in June 2007. I had experience of submitting national protocols for clinical trials to the ethics committee but I had never defended a study at an ethics committee meeting. Attendance at the ethics committee was relatively straightforward but the committee requested that patients be approached in clinic and not by letter which was in the initial proposal. This was the only amendment required. I was recruiting patients from a different hospital from the one in which I worked because most of the laparoscopic surgery was being performed at the joint cancer centre hospital and it seemed more appropriate to recruit patients to my own study if I was not involved in their care. The Research and Development (R&D) submission was a laborious and less structured process than ethics which required constant tracking.

11.3.7 Recruitment

Once the search for eligible patients began it became clear that the number of eligible women was lower than had been anticipated because of a relatively high rate of women with high risk disease. I became concerned about recruitment and managed this by deciding to open the study at a second site. I should have confirmed the pathology data sooner. The laparoscopic surgeon I had worked with in my previous Network agreed for his patients to be offered entry into the study. Site specific approval was sought from the ethics committee but the R&D department delayed the process significantly when the paperwork for the honorary contract repeatedly went missing. Recruitment commenced in February 2008 and was completed in July 2009.

11.3.8 Role Change

In August 2008 I changed jobs again and went into a more strategic role. This did not affect the recruitment or the conduct of the study because I had never been
a member of staff of the recruiting hospital but it did mean that I lost access to my work based supervisors.

11.4 Supervision

Supervision from the University has been a constant support throughout the study. I have detailed records of over 22 formal supervision sessions (summary provided in 11.9) and a chain of e-mail contact and advice with which to monitor my development. I had two workplace supervisors who also offered support and expert clinical and research advice. I attended most of the annual research events at the University, joined the European Institute of Health and Social Sciences PhD support network, presented my study to that group, as well as becoming a member of the London cancer nurses PhD network. It was through supervision that I was encouraged to keep my reflective diary and this commenced in earnest in the middle of 2006.

11.5 Annual Reviews

I have completed four annual reviews reflecting on my progress with the taught course assignments and any difficulties encountered within the year. The contents of which have been used to inform this research log. A summary of the year written against the objectives of the course and my personal objectives from the previous each year provided me with an opportunity to reflect on and discuss what had been achieved and not just on the difficulties encountered.

11.6 Training

As well as the taught modules as part of the doctorate structure, I have received formal instruction in the use of NVivo, SPSS and attended a two workshop on statistics. Reviewing my initial training needs analysis I can update the learning achieved:
- Breadth of understanding of research methodologies – I have an extensive knowledge of phenomenology and an understanding of the principles of qualitative research and the historical and philosophical development of scientific knowledge.

- Goal setting and project management – I have managed discrete projects as part of the doctoral and as part of my work but I continue to have a tendency to work close to deadlines.

- Self discipline- I have managed to complete all assignments, keep the research project going, stand for and continue as Chair of a national Forum at the RCN as well as working full time and having a family. Especially during the last three months of the doctorate, I have improved my ability to refuse projects that I don’t have the time to commit to.

- Presentation skills- this was one of my weakest points on commencing the project and I am now much more comfortable to present, even at short notice and to national groups.

- Listening skills- I have developed a level of understanding of the complexity of facts and the views of others that I am now more flexible in my approach to the views of others.

- Statistics- Although I still could not interpret detailed statistical information, I can now read a research paper and get a general sense of its worth and the significance of the statistics as presented.

My steepest learning curve has been in philosophy where I had limited prior knowledge.
11.7 Publications and Presentations

**Publications**

<table>
<thead>
<tr>
<th>Title: Cervical cancer</th>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Title: Multidisciplinary Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Co-author: Nichola Kane</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Title: Cervical cancer and the HPV vaccination</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Title: An approach to obtaining informed consent from cancer patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Co-authors: Anne Croudass, Heather Phillips, Kim Tye</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Title: Cervical cancer</th>
</tr>
</thead>
</table>

**Presentations**


'Gynaecological Cancers'. St Christopher's Hospice Senior Nurse Education Programme. April 2009

'Delayed cancer diagnosis'. South East Wales Cancer Network Early diagnosis meeting. March 2009

'Delayed cancer diagnosis'. Lancashire and South Cumbria Cancer Network Primary Care Meeting. March 2009

'The NPSA and incident reporting in Chemotherapy' Anglia Cancer Network Senior Nurses Awayday January 2009

'The changing face of Forums'. Colposcopy Nurses Annual Conference November 2008

Cervical Cancer presentation at RCN Congress fringe event - April 2008

Cervical Cancer presentation to MP's at the Houses of Parliament

'Avenues for Support'. International meeting of Jo's Trust a cervical cancer charity. November 2006

'Cancer Politics and Policy' NCRN national training programme. 2005

'The role of the research nurse' National Haematology Cancer Study Day. 2005

'Informed consent for cancer patients' CRNA International Conference. Pisa. 2005 and accepted as a poster at the NCRN national conference.

11.8 Support from Others

Reading through the reflective diary made me realise just how much I had learned from the opportunity to engage with so many different professional and
administrative staff as well as from developing a very different relationship with patients.

11.9 Summary of Supervision

<table>
<thead>
<tr>
<th>Date</th>
<th>Discussion</th>
<th>Action points</th>
</tr>
</thead>
<tbody>
<tr>
<td>26/07/05</td>
<td>Transferred back to practice: Gynaecology cancer: aware of large Australian study: consider backing qualitative onto that study: consider grounded theory using mixed methods: preference or experience: about samples</td>
<td>Prepare proposal. Include reading around methodology. Contact PhD student.</td>
</tr>
<tr>
<td>15/03/06</td>
<td>Service Development Project: linking with new job: passed Policy Analysis: discussion of shape of final proposal: visual plan developed.</td>
<td>Slides for SDP. Prepare for presentation.</td>
</tr>
<tr>
<td>18/05/06</td>
<td>SDP submitted: literature review of laparoscopic hysterectomy: little QoL data: consider experience: consider benign disease: grounded theory or phenomenology.</td>
<td>Send copy of SDP. Consider sample and selection. Consider methodology. Sources of information given. Discuss design at the next meeting.</td>
</tr>
<tr>
<td>28/06/06</td>
<td>Gaining access: met work based supervisors: met surgeon and arranging access: extension on proposal: reading up on phenomenology and philosophy of science.</td>
<td>Send draft proposal.</td>
</tr>
<tr>
<td>02/02/07</td>
<td>Proposal altered in light of feedback: proposal submitted for marking: discussion about 2nd supervisor and qualitative background: discussed alternative perspective: WK still worried about lack of comparison: coherent proposal: need to justify lack of comparator.</td>
<td>LREC R&amp;D and Uni ethics. 60 day approval – submit end of March.</td>
</tr>
<tr>
<td>27/03/07</td>
<td>To meet mentor in clinical practice: chair of LREC: went through COREC form: needs sponsor and insurance form: seems to have thought through ethical issues carefully.</td>
<td>Submit COREC form. Contact head of programme for sponsor form. Focus on methodology and lit review. while we are waiting for approval.</td>
</tr>
<tr>
<td>10/05/07</td>
<td>Discussed COREC form: writing and reading for lit review continues: review methodology and turn into draft chapters.</td>
<td>Submit lit review 08/05/07. COREC meeting.</td>
</tr>
<tr>
<td>20/07/07</td>
<td>Went through ethical procedure and outcome: variation in recruitment as required by ethics committee.</td>
<td>Chase R&amp;D. Uni ethics submission. Background lit review 13/07/07.</td>
</tr>
<tr>
<td>18/10/07</td>
<td>Intro, lit review and methodology- draft form: Good progress in terms of engaging in research; has presented several times; has attended PhD.</td>
<td>Draft work to be sent for comment. Check dates and products for submission.</td>
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<td>Date</td>
<td>Event Description</td>
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<tr>
<td>30/01/09</td>
<td>Extension-Oct 09/Viva Dec 09: Progress- written the introduction which WK/HA gave feedback; LREC processes completed; R&amp;D completed; Honorary contact completed; 4 pts identified for recruitment; TranscriptIon very slow; has found secretary to transcribe; will immerse self in data in corrections and re-listen x1 or 2 times.</td>
<td></td>
</tr>
<tr>
<td>02/12/08</td>
<td>Discussion of the research process: ethics approval for 2nd site; SSA being completed; Interview 5 started; more than evaluate strength of the data; using interview strategy; continue reading in current research; searching databases for relevant literature to explore in light of data.</td>
<td></td>
</tr>
<tr>
<td>07/11/08</td>
<td>Discussion of the research process: ethics approval for 2nd site; SSA being completed; Interview 5 started; more than evaluate strength of the data; using interview strategy; continue reading in current research; searching databases for relevant literature to explore in light of data.</td>
<td></td>
</tr>
<tr>
<td>14/05/08</td>
<td>Apply for amendment to NRES. Consider repeat interviews. Timelines: 9 interviews end of May; complete interviews end of June/July; transcribing analysis end of September/December; apply for 1-year extension.</td>
<td></td>
</tr>
<tr>
<td>10/08/08</td>
<td>Support group still waiting R&amp;D; discussed planned timelines in R&amp;D; discussed potential delays in R&amp;D.</td>
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<td>Date</td>
<td>Notes</td>
<td>Actions</td>
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</table>
| 22/05/09  | Discussed feedback a draft 1-3 chapters: generally well written/very good methodology: Needs to be built on. C/o word allowance; D/A choice of Colalzzi: - defend "being"/bracketing: 13 interviews – is it sufficient? Divide into units 2 decipher/intro/background: Summarise after each theme in literature review. | Consider examiners
Defend (13) through literature
Defend Colalzzi on basis that the work allowed you to use your experience and focus and being
Data analysis – mid Aug 24/08 meet
Daft thesis – mid Sept 5/10 meet |
| 24/08/09  | Analysing the data: has finished transcription, collection: analysis needs finishing: Has begun to read around themes in the literature: Chose to use "excel" to manage data and have discussed rationale for this, needs to justify choice. | Read Morse (1991) on qual. analysis using, word to justify using "excel" for managing the data.
Define themes in data/analysis chapter.
Finish analysis and refine argument.
Justify lack of sub-case analysis.
Draft thesis end Sept 24th
Draft analysis early Sept.
Need to identify journal
Consider time frame at next meeting. |
| 05/10/09  | In-depth feedback given a draft thesis (unfinished discussion):
Rest of month to work on this and is free at work: Research, Publications, Learning/reflection: All to do after analysis while HANK reading work. | Rewrite discussion after identifying key findings at end of chapter:
- relatively happy in procedures.
- anxiety over transferring responsibility
- information shortfall / info rec: choral info rec: surgery.
- Findings apply to other surgical procedures in serious conditions.
Finish discussions and sent both to HA and WK for feedback
Amend section on 1) sample and 2) return interviews.
Should include "upfront" section a contribution to practice and literature. |
| 22/10/09  | Discussed completed work: Sampling and area to prepare for viva: synthesis and conclusion need the most work: explain structure under key findings: contribution to practice: contribution to literature | Send paper, log and overview – 24/10/09
Final draft 02/11/09
Feedback by 23/11/09
Submit early Dec |
Women's experience of laparoscopic surgery in endometrial cancer: a phenomenological study

by

Cathy Hughes RN MSc

Submitted for the degree of Doctor of Clinical Practice

PART TWO

Faculty of Health and Medical Sciences
Division of Health and Social Care
University of Surrey
December 2009
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CHAPTER 12: POLICY REVIEW

Policy:

‘All women with cancer of the ovary, fallopian tube, vulva and vagina and most women with cancer cervix should be referred to the Gynaecological Cancer Centre. Women with early endometrial cancer can be managed in the Cancer Unit’

12.1 Introduction

Cancers of the female reproductive tract include cancer of the ovary and fallopian tube, uterus, cervix, vulva and vagina. Combined they account for about 15,000 cancer diagnoses in England per year (Office for National Statistics 2008a online). From the years 2000 to 2005 major changes took place in the delivery of care for women with these cancers in line with government policy and strategy.

Following the publication of The NHS Cancer Plan (Department of Health (DH) 2000b) cancer services in England were organised into regional Cancer Networks and local Network policy dictated that all women with cancer of the ovary, fallopian tube, vulva and vagina and most women with cancer of the cervix should be referred to the one Gynaecological Cancer Centre based at a single site, an amalgamation of two previously separate gynaecological cancer departments. Women with early uterine and early cervical cancer can be managed ‘closer to home’ in defined Cancer Units.

This policy radically changed service delivery in the locality and resulted in the closure of departments and staff relocation. I have chosen this for my Policy Review because I ‘lived through’ this policy implementation and experienced its effects both personally and professionally. I intend to present some of the national and international influences on the policy, to discuss the background political ideology
and context before going on to analyse the policy using a combination of tools, considering the gender specific issues from a Feminist perspective. I will argue that the national policy was a reaction to a much wider health problem and that the specifics of gynaecological cancer and the needs of all women with gynaecological cancer were not addressed. The policy, as implemented in my locality, altered the dynamics of access to specialist services, by simply changing the focus of 'winners' and 'losers'.

12.2 What is policy?

Policy is described by Colebatch (2002:vi) as 'an idea that flows through all the ways we organise our lives'. It is used widely in public life to shape the way in which it is organised and is a concept which is central to both the practice and analysis of the way we are governed. Policy making involves those in authority making decisions or choices that have status within the group to which they are to be applied (Hanney et al. 2003). Policy can, therefore, take many forms, ranging from national health policies to clinical guidelines.

Public policy is concerned with government allocation of resources in response to public problems which require state intervention. Health policy has been defined as:

'a set of decisions or commitments to pursue courses of action aimed at achieving defined goals and targets for improving health' (World Health Organisation (WHO) 1999:212).

In England, Department of Health (DH) policies are designed to improve on existing arrangements in health and social care. Government health policy often
involves significant changes in service delivery and can be termed 'health systems reform'.

The policy under discussion in this paper is local to one Cancer Network but is based upon national and international policy, guidance and reform. Those in authority in the Network, Trust and PCT managers, made a decision to interpret national policy documents in a way that would allow for significant reallocation of resources and reconfiguration of services. This was done without having defined the benefits or outcome measures for women with gynaecological cancer in the Network or the staff involved in the reconfiguration.

12.3 Policy History – A Timeline

From 1992 to 1997, The Health of the Nation (Department of Health (DH) 1992) was at the centre of health policy in England and framed the planning of services provided by the National Health Service (NHS). This was the strategy document of the Conservative Government which was in power under the leadership of John Major. The importance of this policy document was that it represented an attempt by government to provide a co-ordinated approach to improving the overall health of the population. It was based upon the World Health Organisation Health for All series, commenced in the 1980’s (World Health Organization (WHO) 1999). The Health of the Nation focused on five key areas of public health, one of which was cancer. This document echoed the worldwide movement for health improvement to be implemented through public policies.

The Health of the Nation led to what became known as the Calman-Hine report in 1995; A Policy Framework for Commissioning Cancer Services was produced by the expert advisory group on cancer to the chief medical officers of England and Wales, Dr. Kenneth Calman and Dr. Deidre Hine. The aim of the Calman-Hine
report was to create networks of care in England and Wales which would enable a patient, wherever he or she lived, to be sure that the treatment and care received was of a uniformly high standard 'as close to the patient's home as is compatible with high quality treatment' (Department of Health (DH) 1995:6).

The Calman-Hine report specifically referred to patient centred cancer services that should take into account the views and preferences of patients, families and carers, as well as the views and preferences of professionals. The Calman-Hine report was commissioned by the then Minister for Health, Virginia Bottomley. It was designed to address the delivery of commissioned cancer services but there was no reference to any performance indicators or evaluation.

The Calman-Hine recommendation, relating to this paper, was the development of networks of expertise in cancer care:

'**Designated Cancer Units should be created in many district general hospitals....**

*Cancer Centres should provide expertise in the management of all cancers, including common cancers within their immediate geographical locality and less common cancers by referral from Cancer Units’* (Department of Health (DH) 1995:7).

The Calman-Hine report was followed by the *Improving Outcomes Guidance* (IOG) series which were designed to assist in the commissioning, planning and development of cancer services by cancer site. Clinical Outcomes Groups (COG) were organised in site specific cancers to produce guidance documents based on 'clinical expert consensus and best available evidence', often referred to as the COG or IOG guidance. These documents began with breast cancer in 1996 and the gynaecological cancer guidance was published in 1999 (Department of Health (DH)
1999a). They described best practice in the treatment of the specific cancers, the supportive care and information needs of patients and their carers, and gave clinicians clear instructions on clinical management issues.

In 1997, the Labour Party won the general election which ended 18 years of Conservative Government in the UK. *Our Healthier Nation* (Department of Health (DH) 1998) was a Green Paper published in February 1998, by the new Labour Government. It set out the proposed ‘Contract for Health’ as a partnership between government, local organisations and individuals. This was followed with the White Paper *Saving Lives: Our Healthier Nation* (Department of Health 1999b). The aim of this White Paper, like its predecessor *The Health of the Nation*, was to improve the living conditions and health of individuals in England.

The Labour Government had produced a health policy which had strong continuity with the Conservative policy document. In this document there was one general outcome target in each of the four priority areas, which included cancer. The need to reduce the widening inequalities in health was addressed and preventing avoidable illness was seen as a way to ‘allow concentration of resources on other health conditions’. Improvement in factors which were considered to affect health were targeted, these included individual lifestyle, social and economic inequalities, the environment and access to services. The government aimed to improve the health of the population in terms of lifespan and years free of disease, and to improve the health of the worst off in society, thereby reducing the ‘health gap’. Cancer deaths in people under 75 years of age were to be reduced by a further fifth by 2010.

*The NHS Plan* was published in July 2000 (Department of Health (DH) 2000a) followed by *The NHS Cancer Plan* in September (Department of Health (DH) 2000b)
which set out ‘the first’ comprehensive national cancer programme for England. The
NHS Cancer Plan aimed to bring together cancer care with the investment needed
to ensure that the survival rates in England would be comparable to those in Europe
by 2010. It had four main aims:

- To save more lives
- To ensure people with cancer get the right professional support and care as
  well as the best treatments
- To tackle the inequalities in health that mean that unskilled workers are twice
  as likely to die from cancer than professionals
- To build for the future through investment in the cancer workforce, so that
  the NHS never falls behind in cancer again.

12.4 Policy Analysis

Policy analysis is the generic name for a range of techniques and tools to study
the characteristics of established policies, how these policies came to be in place
and what their consequences are. A variety of models or tools exist that describe the
policy analysis process but they are all similar in their approach, using a series of
systematic steps or headings.

Nicholl and Beyea (1999) described the policy analysis process as helping to
clearly define the problem, understand the context, consider the individuals affected,
analyse the alternatives and evaluate the potential outcomes. Colebatch (2002)
suggests asking a set of fundamental questions when looking at policy analysis:
What was the problem the government was trying to address? What were the
options it as presented with? How did it make the choice? What was the outcome?
Did the policy chosen solve the problem being addressed?
Collins (2005) and Harrison (2001) recommended that there should be a distinction between analysis of policy process and the analysis of policy content and policy implementation. The main focus of process analysis is policy formulation and the main focus of content analysis is the substance of the policy. The framework developed by Bardach (2000) and adapted by Collins (2005), is a tool recommended for less experienced policy analysers with little time. This is a seven-step tool which attempts to: define the context, state the problem, search for evidence, consider the policy options, project the outcomes, apply evaluative criteria and weigh the outcomes.

Harrison (2001) discussed the difficulty in defining policy analysis and considered it to be a general approach rooted in political science. He introduced the social science concept of actors who have different interests and assertions of power relative to each other in the policy process. Walt (1994) and Walt and Gilson (1994) discussed the areas of policy process by defining them as, the structural context, the policy content, the policy actors and the process of decision making. Frenk (1994) presented the health system as a set of relationships among five major groups of actors: the health care providers, the population, the state, the organisations that generate resources and other sectors that provide services.

It is difficult to find a tool that fits the elements for discussion, the specifics of the health policy chosen and my inexperience in the political field. As a result, I have decided to use a combination of the tools and ideas discussed above to analyse the policy using the following headings:

- Define the context
- Identify the issues
- Identify the actors
• Consider the options
• Discuss the outcomes

The policy identified affects women in particular due to the nature of the health problem addressed. Whilst the policy is gender specific the context in which it was drawn up is not. The analysis headings will be considered from a Feminist perspective using the gender specific prompts of a woman-centred policy analysis tool developed by the Woman's Network of Prince Edward Island in Canada (McCardle 2005 online).

12.5 Define the Context

Policy is not developed in a vacuum but in a complex social, political and economic context. Policy context is vital for analysis, why issues are on or not on the agenda are as equally important as the process of analysis. The social context of the political environment should be considered.

For the majority of late 20th Century there were only two political parties in power in the UK, the Conservative or Tory Party and the Socialist Labour Party. The most significant central beliefs of traditional Conservatism involve tradition, human imperfection, organic society, hierarchy and authority, and property. The traditional Socialist belief system involves community, co-operation, equality, social class and common ownership (Heywood 2003).

The inception of the NHS was the result of the expectation of the people after the Second World War and the vision of the Atlee Socialist Labour Government, Aneurin Bevan, and the Beveridge Report on health and social care. The medical profession was initially opposed to the idea of the NHS for fear of losing autonomy and becoming nothing more than civil servants but soon settled into the new system.
with a significant share in power through self-regulation and autonomy (Macpherson 1998).

The politics of medicine are controlled by a triangle of forces, the profession, the civil society and the state. This is not an equilateral triangle, nor is it static. It alters to denote the power that a 'side' has at any given time within what can be described as the policy community (Salter 2004). The NHS is the 'sacred cow' of British society and to keep the NHS intact this triangle must be maintained. Through the political seesaw in the UK government since the NHS inception in 1948, there has never been any real question of disbanding the NHS, for Labour or Conservative governments. The initial popularity of the NHS meant that in the 1950 election, the Conservatives promised to retain it despite the core values of the NHS being more in line with Socialist ideology of equality and common ownership.

Medical authority is rooted in its own ideology which is traditional and hierarchical (Salter 2004). In the policy community of the NHS, medical power has traditionally been dominant. Trust in the authority of medicine is rarely questioned by either society or government. New Right conservatism emerged in the UK in the 1970's. New Right is a marriage between contrasting ideologies, classical liberal economics (particularly the free market) and traditional conservatism. Ideological pressure on the established policy community began with the New Right market principle, the devolution of money and power to the consumer. Although initially the New Right were subordinate to medical interest, they presented the NHS with a new theme, open and more accountable to citizens as consumers.

In the Thatcher and Major governments from 1979 to 1997, the shift in power in this policy triangle went to the state in the form of non-healthcare professionals. They were given the power to run the health service over the medical profession.
Thatcher increased the rhetoric of patient power but considered them beneficiaries of the health service not participants. The anti-professional ideology of New Right used managers as government representatives in the policy community and power triangle. It could be argued that this represented a new shape to the policy community but the triangle remained intact, bureaucrats replacing the Government.

A further change in power took place within the medical profession itself where there was a shift in power from Hospital Consultants to General Practitioners. Klein (1995) described the major shift in thinking about the NHS:

'the balance has shifted from hospital specialists to general practitioners and from providers to purchasers with increasing emphasis on professional accountability and consumerism'.

I would argue, however, that the policy triangle still remained relatively static from the patients perspective and that consumerism was never a real opportunity for the patient to express control but that it gave General Practitioners (GP) the ability to 'purchase' on behalf of their patients, thus increasing the power of the GP.

During this time Clinical Governance was introduced in the NHS and presented a direct threat by NHS managers to the self-regulation of medicine. Clinical Governance is the framework through which organisations are called to account for improving the quality of their services (Scally & Donaldson 1998) and is a move away from professional accountability as the only quality measure in healthcare. Doctors felt threatened and led an effective media campaign against the Government with slogans such as 'What do you call a man who ignores doctor's advice? The Health Secretary.' The Conservative Government lost the 1997 general election to the Labour Party.
The 1997 Labour Government led by Tony Blair, was elected with a promise of reform to traditional labour, referred to as the Third Way. The Third Way accepted the market over the state and that the rights of the community should be balanced with responsibility. The Third Way also conceded that society can be different but still work in harmony and that government should help people to help themselves. The Third Way State should invest in society to boost productivity and the market economy (Giddens 1998).

Patient empowerment in the NHS was a central ideology of the new Labour Government. The NHS Plan (2000a) was designed around the patient, who was to be given more information and even a say in clinical decision making, the very heart of medical power. The NHS was to consider patients as partners in the decision making process and in the policy triangle.

Labour did not abandon the ideology of the previous government, with regard to purchaser and provider roles, contractual relations and managed markets within the public sector, the promotion of the private sector, both profit and non profit making, decentralisation and the introduction of user choice (Collins et al. 1998). The managed markets and competitive principles introduced in the Thatcher and Major eras were evolving to make way for collaboration, partnerships, health alliance and a 'whole systems approach'. Networks were replacing markets.

Trust in the medical profession was challenged when, in 1998, the General Medical Council ruled that two surgeons from Bristol were guilty of professional misconduct for continuing to operate on children despite knowing the death rates were unacceptably high (House of Commons 2001a). This was followed by the Alder Hey inquiry where it came to public attention that body parts were being removed from children and stored by doctors all over the country, without the
In gynaecological cancer individual patients were challenging the professionals through the legal system:

'The worst case of all has been the Kent and Canterbury hospitals NHS Trust where an independent review reported last year that problems in the trust’s former screening services may have contributed to eight deaths, with 30 women needing hysterectomies and over 300 found to be in urgent need treatment. Around 91,000 smear tests needed to be rechecked. As your lordships will be fully aware, just a fortnight ago three women, each of whom developed (cancer) and had to have hysterectomies as a result, won a test case. That case will be followed by others. The damages in that case are yet to be assessed’ (House of Lords 1999).

These cases demonstrated that civil society was ready to see a shift of power away from the traditional self-regulation of the medical profession to more regulation by government and accountability to the public. For government to regulate the professions it needed to find ‘experts’ from within the profession itself.

The final political thread to the context in which this policy fits, lies within the gender specific nature of the policy. Feminism is as much of a political ideology as Conservatism and Socialism. Feminism has evolved to take many forms in the world today but the overt or covert oppression of women remains at the core of the belief system. Liberal Feminists want women to have a proper share within society, Socialist Feminists want to overthrow existing society and Radical Feminists reject formal politics altogether (Adams 2002). Gender is a significant marker of social and economic vulnerability which is manifest in inequalities of access to health care. Analysis should always consider gender issues in policy (Standing 1997). Within Third Way politics, McRobbie (2000) argued that there existed a politics for women
without Feminism. She drew upon the example of the New Labour female MP as one of glamour and make over. These women, she argued, were the women of the middle classes, well groomed, attractive, suburban living, two cars, having a career but deeply consumerist. If these women were left to represent the reality of most women's lives, poverty and inequality, then the power of the female voice in the health policy community would be lost.

12.6 Identify the Issues

There are five main issues relating to this policy and its implementation in my own locality, pre-policy situation, poor cancer survival rates, the role of the specialist, the use of evidence and science, and the complexity of gynaecological cancer.

12.6.1 Pre-policy Situation

Prior to the implementation of this policy, there were four specialist gynaecological cancer departments all working to the clinical management standard of COG guidance. The gynaecological specialist training via the local Medical School also meant that most of the functioning departments had a senior surgeon with a specialist interest in gynaecological cancer with the skills to perform specialist cancer surgery. The newer Consultants were trained according to Royal College of Obstetrics and Gynaecology sub-speciality standards and the more established Consultants were recognised trainers. Clinical and Medical Oncologists attended joint clinics in referring hospitals, up to 50 miles away. Women in the Network could be seen and diagnosed at their local hospital and referred to the closest specialist department, if the local gynaecologist felt a referral was necessary.

Surgery and oncology assessment could be carried out in the local hospital. Chemotherapy and radiotherapy was generally given in two of the four specialist
departments. The specialist centres would take their own 'catchment' population and any patients requiring specialist treatment or care. Referral, however, depended solely upon the decision of the unit gynaecologist. Under this system the elderly and the unwell were less likely to be referred to the specialist departments.

### 12.6.2 Poor Cancer Survival

As a leading industrialised Nation within Europe, the 1995 EUROCARE-1 study (Berrino et al. 1995) report came as a surprise and disappointment to the UK government. The report identified cancer suffers in the UK as generally having worse outcomes than those in comparable European countries. The media quickly compared the UK to socially disorganised and disadvantaged countries in Eastern Europe, accusing the NHS and the government of failure. The NHS was no longer the 'envy of the world' but the shame of the government. This was the NHS that Tony Blair inherited, not the NHS that had been the vision of a Labour Government and symbolic of Socialist ideology.

When Tony Blair commented on the cancer agenda it was accompanied with the discourse of battle:

"UK’s Tony Blair Announces Crusade to Fight Cancer. British expatriate and breast cancer survivor Amanda Thomson considers herself lucky, “When I was diagnosed in 1993, I lived in Brussels, Belgium,” she said “there I had immediate access to a cancer specialist and also received high quality care. In the United Kingdom, I fear there would have been much longer time-lags, and I may not have even seen one.” ....(Tony Blair) announced the beginning of a national crusade against cancer aimed at saving 60,000 lives over the next 10 years” (Steimle 1999).
This article used powerful language to convey the nature of the fight ahead prior to the publication of *The NHS Cancer Plan* (Department of Health (DH) 2000b). It also suggested the precarious nature of cancer treatment in the UK. The use of the words survivor, luck and fear demonstrate this. We can also recognise the emerging theme of ‘specialists’ equating to high quality care.

The EUROCARE figures demonstrated a disparity between European countries in gynaecological cancer. In the UK, cervical cancer survival rates were improving but the UK was not identified as one of the leading countries in gynaecological cancer survival outcomes and this was thought to be due to a wide variation in patient management practices and access to specialist services (Gatta *et al.* 1998).

### 12.6.3 The Role of the Specialist

Throughout the policy documents and the media articles, there appears to be an assumption that ‘specialists do it better’. In the 1995 Calman-Hine report there were two pieces of evidence quoted to support this in gynaecological cancer, research carried out by Junor *et al.* (1994) and Kehoe *et al.* (1994). In the West Midlands Kehoe *et al.* (1994) reviewed over 1600 ovarian cancer patients who were operated on, to assess survival by surgical specialism. Even allowing for the fact that the general surgeons tended to operate on older, less well women, there was a 10 to 29 month improvement in survival benefit for women operated on by a ‘specialist’ as opposed to a general surgeon. Kehoe *et al.* (1994) did not, however, define specialist beyond the level of gynaecologist.

Junior *et al.* (1994) also retrospectively examined the notes of 533 patients, in Scotland, with ovarian cancer and found that those seen and operated on by a gynaecologist, had a low residual volume of disease, were given platinum chemotherapy and referred to a Multi-Disciplinary Team (MDT) at a joint cancer
clinic, were more likely to have increased overall survival. These papers led to the recommendations that specialist multi-professional gynaecological oncology teams should be set up based at cancer centres. These teams were to be responsible for the treatment of all women with ovarian and vulval cancer, the majority of women with cervical cancer and a small proportion of women with endometrial cancer (Department of Health (DH) 1999). The evidence presented as the rationale for this, however, does not support this recommendation. One could argue that based upon the evidence presented, a treatment plan made by an MDT could be carried out by any gynaecologist with a specialist interest in cancer, possibly at a local hospital.

Further considering the evidence of the advantage of specialist treatment, according to Hammond (1987), even in endometrial cancer, which could be treated in the Cancer Unit, referral to a doctor who is ‘fully conversant with current developments in gynaecological cancer’ is recommended and referral to specialist centres is desirable for accurate clinical evaluation and selection of optimal treatment. Hammond (1987) described the need for accurate assessment of patients because of the potential for the discovery advanced disease. However, the survival rates for advanced disease are very low even with additional treatment. The advantage of specialist care, therefore, cannot lie in improved survival for these women. Hammond, however, as a laparoscopic surgeon who would need to treat many cases of endometrial cancer to develop the skills of laparoscopic hysterectomy in order for it to become offered as routine care in endometrial cancer. It could be argued that referral to specialists will allow them to develop their laparoscopic surgical skills. In a second paper considering the specialist skills of the surgeon, Junor et al. (1999) demonstrated that specialist gynaecological oncology surgeons improved outcomes for women with stage III ovarian cancer. At that time, a specialist gynaecological surgeon was defined either by approving training or by
having a 'specialist interest' in gynaecological cancer and regularly performing cancer surgery.

Gillis and Hole (1996) looked at survival outcomes in women with breast cancer for those treated by a specialist and those treated by a non-specialist. The results showed a 9% higher survival rate over five years and an 8% survival advantage over 10 years but women with breast cancer can be treated in Cancer Units, they are not required to be referred to a Cancer Centre under national guidelines. Pitchforth (2002) demonstrated that patients admitted to a non-cancer hospital are less likely to have chemotherapy, which is purported to incur an overall benefit for cancer patients if given. Referral to Cancer Centres is not the only way to ensure access to chemotherapy, the establishment of treatment pathways would also ensure equal access. Grilli et al. (1998) suggested that care appeared to be better in the specialist setting, both when assessed in relation to process indicators and morality but no assessment was made in relation to quality of life.

### 12.6.4 The Use of Science and Evidence

Science has become a potent cultural symbol that is visible in all aspects of modern life and research is seen as an essential mode of communication and persuasion in the public arena as well as in clinical decision making. Research is used as ammunition to support decisions made and implemented. The utilisation of health research in policy making should contribute to policies that may eventually lead to desired outcomes, including health gains (Hanney et al. 2003). There is an increased emphasis on research in policy making but scientific results are typically reported at population level and this disguises variations in outcomes for individuals (Asch & Hershey 1998). This can make policy appear less risky in theory than it is in practice.
Rational policy making assumes policy makers identify problems, then gather and review all the data about alternative possible solutions and their consequences and select the best solution to match the goals. Evidence has to compete with common knowledge and common sense if it is to provide reliable guidelines for better healthcare systems based upon scientific evidence. The rigor of scientific evidence required in clinical practice should equal the rigor required for policy making. The evidence presented for this policy (retrospective case note analysis), however, would not be scientific enough to be considered as good quality evidence in a systematic review.

It can also be said that research evidence does not exist alone outside of its social context. The same research may produce a different decision in a different population under study. The way science is applied has to be contextual. Mooney and Loft (1989) compared different clinical decisions made in different countries and considered the significant impact of culture and ideology on that process. It can be argued that a common objective of health services is to meet the needs of the communities they serve, as effectively and equitably as possible with the resources available. Health policy decision making may be interpreted as clinical decision making writ large and as such essentially both are utilitarian. However, the greatest 'good for society' does not always correspond to the 'greatest good' for the individual.

12.6.5 Gynaecological Cancer as a Complex Issue

It is difficult when assessing the evidence in gynaecological cancer to be consistent because gynaecological cancer is not one disease but several, each with a very different epidemiology, aetiology and disease trajectory. Gynaecological cancers for the COG guidance were assessed as one; no other gynaecological
tumour site was discussed in the way that ovarian cancer had been in the preceding documents. It showed the tendency for all gynaecological problems to be dealt with together as ‘women’s problems’. The perception that the female reproductive tract forms a collective disease is biologically unsound but socially convenient. There is no literature looking at these policy issues from perspective of gender. It is easy to compare female inequality statistically when data can be compared against male data but no gender comparisons can be made in this female only disease group.

The issues facing women with different gynaecological cancers are very different. The social context in which these diseases are found varies considerably: Cervical cancer is associated with lower socioeconomic groups of women. The screening programme in the UK has been very successful and the incidence of cervical cancer is decreasing. Cervical cancer has been strongly associated with sexually transmitted infections and the stigma of promiscuity. Association with the Human Papilloma Virus infection has affected the status of the cervical cancer patient and increased the social stigmatisation of the disease. Women in this group are often younger, may be single parents on benefits or in poorly paid employment. Vulval cancer is generally seen in elderly women and occurs, at its peak, in women in their eighties. These women are often widowed, living alone and have complex health needs due to the multiple chronic illnesses associated with the elderly. Endometrial cancer generally affects postmenopausal women who may have the associated health problems of diabetes and obesity. Ovarian cancer tends to affect middle-class women who have not had any pregnancies or children. The way that these diseases present and are managed clinically is significantly different and so is the social context in which they generally occur (Blake et al. 1998).
12.7 Identify the Actors

The idea of making well informed and rational decisions between possibilities in a scientific manner is set against the real world battles for control of agendas by interest groups with shifting power bases (Bond 1999). Special interest groups of all sizes and causes interface with the legislative process to influence outcome at every level of policy development, implementation and evaluation (Parsons 2002). In the policy community under review in this paper, the actors are many and varied and to take the analogy one step further, they have not all been given a speaking part. This community consists of patients (which could also be seen in the power triangle as the public), managers and healthcare providers, the state and the medical profession (Frenk 1994).

12.7.1 Patients

When considering the dominant patient voice which has influenced this policy, it has been primarily driven by one group of patients, women suffering from ovarian cancer. The reasons for this lie in the epidemiology, aetiology and disease trajectory as well as the high cost of treatment. As mentioned earlier, an ovarian cancer patient is typically well educated and middle class. For example:

'I am 31 years old, have a daughter of 3 and a loving husband. I have led a charmed life. I have had a very happy, loving childhood, graduated from Cambridge with a degree in botany, trained as a science teacher, and started a career in environmental education. I am active and attractive and love to live. The greatest inconvenience of my life is having ovarian cancer .... (Sarah Dickinson 1996)

Women with ovarian cancer are often childless (as a risk factor of the disease) and wealthy with careers that have never been abandoned or broken to have a family. These are women who could possibly associate themselves with the New
Labour MP's described by McRobbie (2000). They have an articulate voice and a like-minded receptive audience. Cancer of the ovary can also be treated for many years during which time these women will be relatively well and fit to campaign for their cause. They are also treated many times with very expensive chemotherapy and have little difficulty in obtaining financial backing and support from drug companies. Without the ties of children, these women may also be less imbedded in their local community and travel to specialist cancer centres not so much of an issue, practically or financially. Sarah Dickinson goes on to say:

'I must live for the present, yet prepare for an uncertain future because the doctors have told me I have only another year to live. And there is always the hope that the big guys at the Royal Marsden Hospital will buy me time.......Some (patients) weren't even being seen by a medical oncologist and getting the proper treatment, which I thought was frightening.'

Sarah Dickinson set up an ovarian cancer charity, Ovacome, which successfully targeted the Government at the highest level.

The reality for most women, however, is that they work in the public sector, are in part time employment, have lower pay and more welfare needs (Office for National Statistics 2008b online). Women with cervical cancer tend to be from the lower socioeconomic spectrum, these women have more children and are often single parents. There are increasingly more women bringing up a family alone and children in lone-parent families were more likely to live with their mother than with their father; in 2001, nearly nine out of ten of the lone-parents were lone-mothers (Office for National Statistics 2003 online). Although the number of lone-mother families increases across the country, London has the highest number. When a woman with children is diagnosed with cancer, the practicalities of treatment can
have a devastating effect upon the children and the family. Good quality medical care close to home would be a priority for these women from a practical, social and financial point of view. Adequate and safe medical care locally may be preferential to expert care at a distance.

The concentration of poverty among women is higher and particularly marked in later life (Arber 1998). Older women are less likely to have a spouse for support; in Britain, 61% of women are living alone by the age of 75 years (Office for National Statistics (ONS) 2009). Vulval cancer is more prevalent in women over 75 years and transfer to a Cancer Centre can lead to social isolation, hardship and disorientation.

Policy is not neutral and undertakings to be implemented for the common good and can be viewed as a vehicle which promotes the values, understandings and ultimately the interests of a particular group (Bond 1999). It is important to consider those who stand to gain and who lose out in a policy.

The referral of women from outside London into a Cancer Centre is contrary to the evidence from patient experience research. When considering patient experience of cancer, London had a less positive response than the rest of the country. In defence of the cancer agenda Sir Nigel Crisp, Chief Executive at the Department of Health, acknowledged that patients had a worse impression of services despite equal survival rates. He felt this was probably due to staffing issues in London, high staff turnover and continuity of care but also possibly a higher expectation (House of Commons 2005). Result from patient surveys include people’s judgement of their interaction with the system which they compare with expectation. Rich people are often less satisfied with the same system because it does not allow for ideology or culture and differences in expectation (Murray 2001).
12.7.2 The Medical Profession

From the medical perspective, the concept of more specialisation demonstrates a belief in hierarchy, which is in keeping with Conservative medical ideology. This creates tiers of medical staff based upon 'higher skills' and shifts the balance of power back to the professions. The professions are taking on board the idea of super specialisation and regulation, for example, to have more explicit and stringent training requirements before surgeons can carry out procedures independently. This demonstrates the professions collective acceptance of responsibility of maintaining competence in practice (Klein 1998) but it also shows the desire to remain elite and in control.

The medical profession views science and technology as leading the way for society. Julio Frenk (1995), writing about a study in Mexico, considers health service reforms and policy analysis in the context of rapid changes, increasing technology and increasing expectation of the population. With educational changes, increased knowledge, technological ability and cultural changes there is a raising expectation of quality of life. The public are willing to accept science based knowledge and evidence to lead political changes. Medics are still seen as leaders in scientific knowledge and protect their status through self-regulation and autonomy. Cancer Centre medical staff are responsible for setting guidelines by which all other medics are required to manage their patients. This maintains the medical power in the policy community, even though this is in favour of the specialist over the generalist.

12.7.3 The Government

The 1997 government of Tony Blair set out to tackle inequalities and inequities in health, proof of their Socialist roots and their ability to manage and protect the NHS. In gynaecological cancer, in developed countries, the main inequalities arise
from the aetiology of the disease and the policies around primary prevention. The real issues are global. Frenk and Gome (2002) discuss the globalisation of health and the challenges faced collectively. Cervical cancer is at epidemic proportions in underdeveloped countries but on the decline in the UK because of the National Screening Programme (Blake et al. 1998). It is also associated with social stigma because of its association with sexual promiscuity and multiple partners. Ovarian cancer, however, is a major cause of cancer death in the developed world (Parkin et al. 2005). The government needed to show the electorate that it was committed to removing inequality, but the inequality that made the UK the poor relation in Europe, not global inequality. Understanding inequalities in non-communicable disease such as cancer is challenging (Leon et al. 2001) and, in gynaecological cancer, the government had gone for a 'quick fix' based upon scant evidence in gynaecological cancer.

12.8 Consider the Options

In my local Network an options appraisal took place which was led by the Cancer Network team. The options were developed by the senior management team and essentially consisted of basing the Centre at one hospital site. No consideration was given to strengthening local services in order to provide care closer to home. The options appraisal went to local community groups and several meetings were held. The final step in the options appraisal was to have a team of 'experts' read the proposals from each hospital site and make a decision based on the 'bids'.

12.9 Discuss the Outcomes

With the publication of the Improving Outcomes Guidance (IOG) in Gynaecological Cancers (Department of Health (DH) 1999a) and The NHS Cancer
Plan (department of Health (DH) 2000b), the Cancer Network and the acute Trusts set out to assess the implications of these policy documents locally. It was clear that the locality had over and above the required services to meet the new standards. It was decided that the Cancer Network should concentrate specialist services on a single site. This can only be seen as cost saving. The argument was based around further investment being better spent on one site. Two of the hospitals decided to effectively transfer Networks, which left the other two hospitals to bid against each other. The bids were assessed by an outside team and the ‘winner’ decided upon by the Network board and Trust management teams. Staff involved in this process were required to move hospital sites or leave. One senior nurse and two Consultants decided to leave.

The Unit clinicians were no longer permitted to operate on gynaecological cancer patients except in early endometrial cancer, very early cervical cancer, in an emergency situation or for benign intent. Women had no choice but to be referred to the Cancer Centre to be seen, assessed and treated. Patient choice on an individual level no longer existed.

The reality of the outcome of this policy for some of the women affected by gynaecological cancer can be seen through their stories:

Mrs B. was admitted to her local hospital via Accident and Emergency with a distended abdomen. She was referred to the gynaecologist specialising in gynaecological cancer at her local hospital – a cancer unit. The gynaecologist diagnosed extensive pelvic and abdominal cancer of probable ovarian origin. According to the network policy the gynaecologist referred Mrs B. to the cancer centre 50 miles away. On admission to hospital it was clear that Mrs B. was terminally ill. She was investigated and discovered to have extensive endometrial...
cancer, not ovarian. The treatments for such cancers are different and the cancer centre had made a significant change to the diagnosis and this could be seen as evidence of the success of centralisation. However, Mrs B. was too ill for any treatment. She was in the terminal phase of her life. She was now too unwell to be transferred home or back to her local hospital. Her husband, who was unable to drive, caught the train every day to visit her at considerable cost. They had no children or close family and the distance was prohibitive for friends to visit. She died in a hospital far away from her friends and her home. Her husband had to return to central London to register her death.

Ms D. was a 27 year old lady with cervical cancer. She was not married and had three children. She had an on-off relationship with the father of her eldest child. She had been diagnosed at her local cancer unit and referred for treatment. She had surgery but this showed that the disease had spread to the lymph nodes outside her pelvis. She was given chemotherapy and radiotherapy which necessitated regular visits to the cancer centre. She needed to stay overnight due to the travelling distance and lack of support. Every time she was admitted to hospital her children had to be placed into ‘care’. Every time her eldest daughter went into care she became disruptive and difficult to manage. Medical and nursing staff from the cancer centre remained in contact with the social care workers but were unable to attend any case conferences or meetings because of the distance. Ms D. was treated at the cancer centre for three years before she was treated locally for palliative care in the last two months of her life.

In order to ensure access to specialist services the government has pursued a policy of control and prescriptive practice. This has been to the benefit to many women nationally but has also been to the detriment of others. In my own Cancer
Network it could be argued that most women with gynaecological cancer were disadvantaged by the change in policy.

12.10 Conclusion

Health policy is designed to improve existing arrangements in health and social care. The aim of government policy documents relating to this local policy was to improve overall access to treatment across the country for women with gynaecological cancer. Access to high quality services in this Cancer Network was already in place for all women in the Network but the commissioners saw an opportunity to rationalise and reduce the overall cost of services in the locality.

Under the previous system, women had access to specialist services controlled by their local gynaecologist. Under the new system all women, irrespective of preference or social need, were referred to the single Cancer Centre, under the control of Network policies and protocols.

These policies affected different groups of women in different ways and have been driven by interested parties within groups of patients, professionals and the Government. Policy can only be made when the social and political climate permit. It is always influenced by power within the policy community where the benefits for one group will potentially always be to the detriment of another.

The improved survival targets will be measured in 2010 and gynaecological cancer will form part of the assessment. The benefit of this policy in relation to the targets will be addressed but, so far, there is no evidence of the success of the policy because there were no evaluation measures devised before its implementation.
12.11 References


13.1 Introduction
The service development project informed the main study but was distinct from it. It considered the issues of access to the specialist services required for women to be offered laparoscopic surgery. The main study considered the experience of the women who were offered the surgery and the service development project considered the reality of access to the service. This project resulted in a Powerpoint presentation of five main slides and 1000 words which formed the basis of an oral presentation.

13.2 Patient Choice in Endometrial Cancer

Patient Choice in Endometrial Cancer
Cathy Hughes
Defining the Question and Service Improvement.

- Why are only some women offered laparoscopic hysterectomy for endometrial cancer?

- Aim: to increase the number of women offered the choice of laparoscopic surgery for endometrial cancer.

Laparoscopic hysterectomy was first described in the late 1980s (Reich et al. 1989). For seventeen years it has been researched and discussed in the literature but is still not routinely practiced (Garry et al. 2004; Nezhat et al. 1992; NICE 2003; Raju & Auld 1994; Reich & Roberts 2003; Vaisbuch et al. 2006).

In the Network Cancer Centre where I work, I observed that some of the specialist surgeons offered laparoscopic hysterectomy to women with endometrial cancer, while others did not.

As patient advocate and having responsibility for ensuring that women are fully informed about their disease and management options, I felt that this was a potential area of inequality and inequity.
I set out to explore the facts, factors and context of this disparity with the ultimate aim of increasing the number of women offered laparoscopic surgery for endometrial cancer within the Network.

**13.4 Slide 2: Exploring the Issues**

The central theme of this project was patient choice. I used the PEST analysis model (Table 13.1) and included other factors but excluded some factors which make up the PESTELI model (Ecological, Legislative, Industry).
13.4.1 PEST Analysis Model

13.4.1.1 P = Political

Improving Outcomes Guidance (IOG) recommended the reconfiguration of cancer services (NHS1999). In gynaecology, radical surgery is generally performed for cancer. Before IOG General Hospitals had a surgeon considered to be ‘skilled’ enough to perform such surgery. Post IOG women requiring complex surgery were referred the Cancer Centres, depriving unit gynaecologists of the most challenging surgery. Endometrial cancer was excluded from centralisation because the surgery involved is little more than a simple hysterectomy. A shift in power to the Cancer Centre caused a tension which still remains.

13.4.1.2 E = Economic/Managerial

Laparoscopic hysterectomy takes longer to perform and uses expensive disposables but this is offset by earlier discharge (Bornstein & Shaber 1995; Campbell 2003). The Trust aims to reduce inpatient stays by 10% and to increase surgery. Funding follows the patient, an important issue for a Foundation Trust. Excluding endometrial cancer, the reconfiguration of gynaecological cancer to Cancer Centres cost the nation and estimated £7 million.
13.4.1.3 **S = Sociocultural/Ethical**

Patient choice respects autonomy and the capacity for self determination, a fundamental principle of medical ethics (Parker 2001). Evidence-based medicine/choice is seen as the way forward (Mort 2001; Parker 2001; Rogers 2002) but medicine has been based upon tradition and opinion. Patients can find choice confusing and burdensome. I believe that the ethical principle of equipoise should apply in clinical choice, not just in research (Lilford 2003; Weijer et al. 2000). It is difficult to discuss this issue with patients because of highlighting a potentially unavailable service.

13.4.1.4 **T = Technological/Surgical Skill**

Only Centre surgeons perform this surgery. All women could be referred, rendering the Unit surgeon a diagnostic technician, questioning the viability of Cancer Units. Not all centre specialists are able to perform this operation. Expert surgeons may need to retrain and refer ‘their’ patients to junior colleagues. The research literature implies that laparoscopic surgeons are more skilled (Eltabbakh 2000; Frumovitz et al. 2004; Shein et al. 2003a; Shein et al. 2003b).

13.4.2 **Endometrial cancer**

About 5,500 women are diagnosed annually in the UK (Cancer Research UK 2009). Most with early disease are cured with surgery alone. Surgery involves removal of the uterus (hysterectomy) and ovaries, sampling the peritoneal fluid, possibly a pelvic lymphadenectomy and radiotherapy for high risk tumours (Bender et al. 2000; NHS 1999). Hysterectomies are open, vaginal, or laparoscopic. In endometrial cancer vaginal hysterectomy is not recommended. Studies continue to examine the risks of laparoscopic surgery but it is widely accepted that this technique is safe (Gil-Moreno et al. 2006; Garry et al. 2004; Kueck et al. 2006; Tozzi et al. 2005; Vaisbuch et al. 2006). There is little evidence to suggest harm, NICE
(2004) reviewed studies on over 100,000 women (Table 13.2). The debate continues over potential benefits. In a large clinical trial (ASTEC) laparoscopic surgery was not considered a confounding factor.

Table 13.2: Numbers of participants in laparoscopic hysterectomy studies (Based NICE (2004) data)

<table>
<thead>
<tr>
<th>Trial Type</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Randomised controlled trial</td>
<td>1901</td>
</tr>
<tr>
<td>Non-randomised controlled trial</td>
<td>29030</td>
</tr>
<tr>
<td>Case studies</td>
<td>80496</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>111427</strong></td>
</tr>
</tbody>
</table>

13.4.3 Role

I have responsibility for the quality of information given to women to make informed choices but I need to function within the team to influence change, improve quality and ensure effective working relationships with colleagues.

13.4.4 Methodology and Data

- Information required to best answer the questions.
- Information required to persuade others and to evaluate change.
- Availability and accessibility of data from direct sources and gatekeepers.
### Data Summary

- All four surgeons said they could perform laparoscopic hysterectomy.
- Two learnt this as part of basic training.
- All four said they offer women with endometrial cancer this type of surgery.
- Three felt that patients should be given the choice.
- Two said they were increasing their use of this technique in the interests of development.

- 94 women in total
- Average age 64.4 years
- 69% local Network
- 30% operated upon by specialist surgeon
- 6% had laparoscopic hysterectomy
- 7% operated upon at RMH
- 10% appeared to have at least been offered laparoscopic surgery
- 77% were operated upon in the units with no access to laparoscopic skills

I hoped to gain insight into reasons for not offering choice but also to identify allies, change champions and areas of contention or resistance. I considered who was offered choice and why choice may not be offered, in two ways:

- Consultant interviews
- Retrospective surgical audit

The four centre surgeons were interviewed individually (Table 13.3 and 13.4).
Table 13.3: Consultant interviews

<table>
<thead>
<tr>
<th>Question</th>
<th>Surgeon 1</th>
<th>Surgeon 2</th>
<th>Surgeon 3</th>
<th>Surgeon 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you perform major laparoscopic surgery?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Did this procedure form part of your basic training?</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Do you currently offer women the choice of laparoscopic surgery?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Do you feel all women should be made aware of the options and given the choice?</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Table 13.4: Other Issues Raised by the Consultants

Other Issues Raised by the Consultant Interviews:
- Three surgeons said they had already completed additional training and one discussed the need to do more supervised cases.
- One surgeon felt that the decision was his alone, that he would offer this to women if he felt it was right for them. He considered open hysterectomy to be as 'good an option' and it was his opinion patients came for.
- Two of the surgeons commented that they are increasingly offering this type of surgery as a positive and inevitable development.

I completed an audit to establish practice at one of the Cancer Centre hospitals. I reviewed the case notes of women seen for the first time with endometrial cancer over the year January 2005 to December 2005 (Table 13.5). A spreadsheet recorded, age, whether in the Network, what surgery, where and by whom (Appendix 13.1).

13.5.1 Summary of Audit Findings
- 94 women presented with endometrial cancer in 2005, \( n = 94 \)
- Age range 37 to 94 with an average of 64.4 years (Figure 13.1)
- Two of the centre gynaecologists were actually performing laparoscopic hysterectomy.
- Two patients had part of the surgery done laparoscopically
- No unit surgeon had performed laparoscopic surgery.
- 87% of Network patients had high risk disease (34% Network average).

Only 10% of women could be identified as having been offered laparoscopic hysterectomy.
Figure 13.1: Age of Patients

Age of Patients admitted with Endometrial Cancer in 2005 n=94

Table 13.5: Table of results: audit of women with endometrial cancer seen at one Cancer Centre Jan. to Dec 2005.

<table>
<thead>
<tr>
<th>Patients</th>
<th>Number</th>
<th>Percentage % of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>From the Network</td>
<td>55</td>
<td>59</td>
</tr>
<tr>
<td>From outside the Network</td>
<td>29</td>
<td>31</td>
</tr>
<tr>
<td>Operation by specialist surgeon</td>
<td>28</td>
<td>30</td>
</tr>
<tr>
<td>Operated on at Centre Hospital</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Had Laparoscopic Hysterectomy</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Had choice documented</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Had Open surgery</td>
<td>73</td>
<td>77</td>
</tr>
<tr>
<td>Had High grade disease</td>
<td>91</td>
<td>97</td>
</tr>
<tr>
<td>Had Surgery alone</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>
Few women were actually offered laparoscopic hysterectomy. The issues are multiple and complex, existing at medical, financial, political, social, personal and ethical levels. Although this is a planned change, there is evidence from the surgeon’s interviews and the future of cancer services, that this is also an emergent change: one could argue that all organisational-level change contains an emergent element.

The change process here is developmental: change that enhances or corrects existing aspects of an organisation, focusing on the improvement of a skill or process (Ackerman 1997). For most change the impact is complex, multidimensional and multifactoral reflecting the whole systems thinking routinely employed in the NHS. The simple notion of patient choice is made up of many
complex contributing factors which can not be taken apart and treated independently.

Lewin (1951) described a technique to affect change using a force field analysis. The driving forces are those attempting to push in a particular direction, tending to initiate change and restraining forces acting to restrain or decrease the driving forces.

Increasing the driving forces can cause tension but with a corresponding reduction in the restraining forces change can effectively take place (Figure 13.2).

Figure 13.2: Based on Lewin (1951).

**Driving Forces:**

- Patients - via information leaflets, national and local awareness, endometrial cancer website and local support group.
- Hospital management – meetings with clinical audit and Medical Director.
Reduce resistant forces:

- In Units - specialist nursing forum to raise the profile of laparoscopic surgery.
- Spurred on two centre surgeons by questioning current practice.
- Suggest suitable patients for laparoscopic surgery at the team meeting.

13.7 Slide 5: Change Evaluation

The model for improvement by developed Langley et al. (1992) is a tool designed for accelerating improvement and has been used extensively by the Cancer Collaborative and for NHS Service improvement (Slide 5).
13.7.1 Model for Improvement

<table>
<thead>
<tr>
<th>What are we trying to accomplish?</th>
<th>Increase patient choice for women with endometrial cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>How will we know that a change is an improvement?</td>
<td>Increased numbers of women having choosing to have laparoscopic surgery. Documentation of choice.</td>
</tr>
<tr>
<td>What change can we make that will result in improvement?</td>
<td>Patient information Nurse information Team meeting agenda</td>
</tr>
</tbody>
</table>

The PDSA cycle is intended to test the change in the real work setting:

<table>
<thead>
<tr>
<th>Plan – planning it</th>
<th>First wave completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do – trying it</td>
<td>This process has begun</td>
</tr>
<tr>
<td>Study – observing the results</td>
<td>Audit and then re-audit</td>
</tr>
<tr>
<td>Act – plan the next cycle</td>
<td>To do</td>
</tr>
</tbody>
</table>

13.8 Conclusion

My research project aims to explore the experience of women having this surgery and the arguments discussed here will inform my main project, my main project will inform women to enhance patient choice.
13.9 References


Gil-Moreno A., Díaz-Feijoo B., Morchón S. & Xercavins J. (2006) Analysis of survival after laparoscopic-assisted vaginal hysterectomy compared with the conventional abdominal approach for early-stage endometrial carcinoma: a


13.10 Appendix: Audit Spreadsheet

<table>
<thead>
<tr>
<th>REFERRAL NETWORK</th>
<th>SURGERY</th>
<th>TREATMENT</th>
<th>HOSP</th>
<th>SURGEON</th>
<th>OFFERED I</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>YES</td>
<td>TAHBSO</td>
<td>RTI</td>
<td>KT</td>
<td>MD</td>
</tr>
<tr>
<td>3</td>
<td>NO</td>
<td>TAHBSO</td>
<td>*</td>
<td>KT</td>
<td>unknown</td>
</tr>
<tr>
<td>4</td>
<td>YES</td>
<td>TAHBSO</td>
<td>*</td>
<td>KT</td>
<td>unknown</td>
</tr>
<tr>
<td>5</td>
<td>NO</td>
<td>TAHBSO</td>
<td>*</td>
<td>KT</td>
<td>unknown</td>
</tr>
<tr>
<td>6</td>
<td>YES</td>
<td>TAHBSO</td>
<td>*</td>
<td>KT</td>
<td>unknown</td>
</tr>
<tr>
<td>7</td>
<td>NO</td>
<td>PRIVATE</td>
<td>Laparotomy, inoperable</td>
<td>*</td>
<td>KT AN</td>
</tr>
<tr>
<td>8</td>
<td>YES</td>
<td>TAHBSO</td>
<td>RTIachji</td>
<td>MD</td>
<td>PC</td>
</tr>
<tr>
<td>9</td>
<td>YES</td>
<td>TAHBSO</td>
<td>Branchy</td>
<td>MD</td>
<td>PC</td>
</tr>
<tr>
<td>10</td>
<td>NO</td>
<td>TAHBSO</td>
<td>Branchy</td>
<td>MD</td>
<td>PC</td>
</tr>
<tr>
<td>11</td>
<td>NO</td>
<td>PRIVATE</td>
<td>Laparoscopic</td>
<td>*</td>
<td>KT MD</td>
</tr>
<tr>
<td>12</td>
<td>YES</td>
<td>TAHBSO</td>
<td>Branchy</td>
<td>MD</td>
<td>PC</td>
</tr>
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14.1 Abstract
Aim: This paper reports on a study using a qualitative approach to bring the patient perspective into the evidence base on laparoscopic surgery for endometrial cancer.

Background: Laparoscopic surgery is increasingly used to treat early endometrial cancer. It is associated with low levels of morbidity and considered safe as cancer surgery but research on quality of life and women's experience is limited.

Method: Heideggerian hermeneutic phenomenology was used to explore the experiences of 14 women who had undergone the procedure in two South of England cancer centres between February 2008 and July 2009. Unstructured interviews were taped, transcribed and analysed using Colaizzi's framework.

Findings: A phenomenological description emerged from five identified themes: having cancer, information and support, independence, normality and transfer of responsibility to the surgeon. The experience of laparoscopic surgery is overshadowed by the presence of cancer. Fear and lack of knowledge play a significant role in the need to entrust the surgeon with the responsibility for decision making. Unmet information needs are individual but focus on what will be done, what to expect and the practicalities of being in an unfamiliar situation and environment. Loss of control, vulnerability and dependence are associated with illness and surgery but early postoperative mobility and reduced pain associated with laparoscopic surgery facilitate a rapid return to independence and normality.
Conclusion: Healthcare professionals should deliver care in early endometrial cancer that recognises the significance of the cancer diagnosis, the role of the surgeon, the need for practical information and the use of treatments that reduce dependency.

Key Words: Nursing, Laparoscopic hysterectomy, Phenomenology, Interview, Cancer care, Women's Health, Endometrial cancer.
14.2 Summary Statements

14.2.1 What is already known about this topic

- Endometrial cancer is a relatively common cancer which is effectively treated, in the majority of cases, with hysterectomy.
- Laparoscopic hysterectomy was first performed in the late 1980s and women are increasingly offered this type of surgery for endometrial cancer where there is a surgeon able to perform the procedure.
- Research to date has concentrated on safety and efficacy, cost and complications but data is limited on quality of life and from the woman's perspective.

14.2.2 What this paper adds

- A phenomenological description of laparoscopic surgery for endometrial cancer from women who have undergone the procedure.
- Fear of cancer overshadows and shapes the experience which includes the need to trust the surgeon with decision making.
- Unmet information needs focus on the practicalities of treatment and a rapid postoperative return to self-care enhances independence and normality.

14.2.3 Implications for practice and/or policy

- Care should be delivered to women with endometrial cancer that recognises the significance of the cancer diagnosis and their lack of knowledge of cancer and surgery.
- Healthcare professionals caring for women with endometrial cancer should acknowledge the role of the surgeon and the dynamics of the patient-surgeon relationship in a life threatening illness where the surgeon has the ability to cure the disease.
- Women with endometrial cancer should have equal access to laparoscopic surgery.
14.3 Introduction

Cancer of the uterus is the seventh most common cancer in women worldwide with almost 200,000 new cases per year. It is more common in Western industrialised nations, with the highest incidence in North America and Western Europe and the lowest in Western Africa and Asia (Parkin et al. 2005). In the UK, it cancer is the most common gynaecological cancer and in England just under 6000 women were diagnosed with the disease in 2006 (Cancer Research UK (CRUK) 2009).

The lining of the uterus, or endometrium, is the usual site for the development of uterine cancer. The exact cause is unknown but over 90% of cases occur in women over the age of 50 years (Parkin et al. 2005) and obesity is the most important risk factor accounting for about 40% of the incidence (Boyle & Levin 2008). It is associated with diabetes, hypertension and continuous or prolonged exposure to oestrogen in the absence of sufficient levels of progesterone (Emons et al. 2000). The incidence of endometrial cancer is increasing, primarily due to the increase in obesity and life expectancy across the world (Boyle & Levin 2008).

Cancer mortality is generally higher in lower socioeconomic groups (Kogevinas et al. 1997) and the survival rate for uterine cancer ranges between 67% and 82% (Parkin et al. 2005). The European average was around 78% for women diagnosed between 1995 and 1999 (Sant et al. 2009) and the latest figures for England (2000-2004) show an average survival rate of 77% (Office for National Statistics (ONS) 2005 online).

14.4 Background

Women with endometrial cancer commonly present with vaginal bleeding after the menopause. This symptom appears early in disease development and most
women present with Stage 1 disease where the cancer is confined to the uterus (Benedet et al. 2000).

The recommended treatment for Stage I endometrial cancer is to remove the entire uterus (a total hysterectomy) together with both fallopian tubes and ovaries (bilateral salpingo-oophorectomy) using a midline incision in the abdomen. A sample of peritoneal fluid should be taken at the time of surgery and any decision about removing draining lymph nodes made on the degree of risk of cancer spread (Benedet et al. 2000). Not all gynaecological surgeons use a midline incision and in the ASTEC multinational endometrial cancer study, 43% used a transverse incision (ASTEC Study Group 2009).

However, it is now possible to remove the uterus using a laparoscope and since the first laparoscopic hysterectomy was performed in 1988 (Reich et al. 1989), the number of women having this procedure has increased. In endometrial cancer, the surgery required to adequately stage and treat the disease can also be performed laparoscopically (Childers et al. 1993). Women are being offered this treatment by some gynaecologists but this is not yet widespread practice and only 7% of women entered into the ASTEC study had laparoscopic surgery (ASTEC Study Group 2009) and about 10% of the US Society of Gynecologic Oncologists performed laparoscopic hysterectomy for endometrial cancer in 2002 (Frumovitz et al. 2004). Although the number of surgeons offering this surgery is increasing, in a repeat audit of the Society of Gynecologic Oncologists in 2007 this figure had risen to 43% (Mabrouk et al. 2009), access remains limited. In England, early endometrial cancer is the only major gynaecological cancer surgery that is not required to be performed by an accredited gynaecological cancer surgeon (National Cancer Action Team 2008).
14.5 Literature Review

The role of a pre-study literature review is debated in phenomenology. In this study, an initial review was carried out to ensure the issues surrounding laparoscopic surgery for endometrial cancer were understood, that no similar studies had already been reported, to provide shape and focus to the study and to ensure this could be demonstrated for ethical approval. The potential to bias an inductive process was recognised and the benefits of this approach have been acknowledged by other authors (Morse & Field 1996; Lowes & Prowse 2001; Carpenter 2007).

The review of the literature relating to laparoscopic hysterectomy identified four main themes, safety and efficacy, complications, cost and quality of life. Despite being a relatively new procedure, laparoscopic hysterectomy is considered to be safe but it is still too early to comment on long-term survival for women with cancer (Walker et al. 2009). The reported intraoperative complication rates are about the same as open surgery but lower postoperatively, 14% compared with 21% (Walker et al. 2009). Older women and those who are obese appear to be the groups who stand to gain most benefit from this type of surgery (Ballesta López et al. 2003; Yu et al. 2005; Willis et al. 2006).

Reports on cost are mixed with suggestions that, in relation to open hysterectomy, the laparoscopic route is more expensive (Lumsden et al. 2000), about the same (Sculpher et al. 2004) or has the potential for cost savings (Raju & Alud 1994). Quality of life has been addressed in relation to pain, mobility, length of hospital stay and return to work but only seven studies used a recognised quality of life measure. Three of these studies demonstrated no difference in comparison with open surgery (Ellström et al. 2003; Lumsden et al. 2000; Persson et al. 2006) and
laparoscopic surgery showed some advantages in the remaining four (Garry et al. 2004; Zullo et al. 2005; Kluivers et al. 2007; Kornblith et al. 2009). However, these advantages were not sustained over time and evidence of statistical significance was limited but length of stay was shorter in the laparoscopic cohorts. No studies considering this technology from the perspective of women undergoing the procedure were identified.

14.6 The Study

14.6.1 Aim

The aim of this study was to develop an understanding of the experience of having laparoscopic surgery for endometrial cancer from women who had undergone the procedure.

14.6.2 Approach

The philosophy of phenomenology guided the approach and conduct of this study. The main concepts of phenomenology, which seek to understand the relationship between the world and the senses that experience it, originate with the philosopher and mathematician Edmund Husserl (Husserl 1900-01). Husserl was concerned with how we interact in the world as conscious beings and his ideas were refined by Martin Heidegger who shifted away from consciousness to being: Heidegger described humans as embodying how to be, rather than thinking how to be (Heidegger 1962). Developing an understanding of the lived experience marks the philosophy of phenomenology as a research method.

In the development of this research, the main considerations around the philosophies of Husserl and Heidegger concerned phenomenological reduction or 'bracketing' and hermeneutics or interpretation. Husserl described the need to
remove preconceptions from the research process, to bracket them out as a way of removing bias. However, Heidegger considered it impossible to remove preconceptions since we are beings engaged in the world (being-in-the-world) unable to remove ourselves as subject contemplating object (Dreyfus & Wrathall 2006). In Heideggerian phenomenology preconceptions are identified and recognised but not bracketed out (van Manen 1990). The second phenomenological feature associated with Heidegger is hermeneutics. Heidegger (1962) advocated the use of hermeneutics because he believed the lived experience to be an interpretive process. In this study a Heideggerian hermeneutic approach was seen as the most appropriate way to develop an understanding of laparoscopic surgery as interpreted by women who had lived the experience, recognising but not removing the knowledge and experiences of the nurse researcher.

14.6.3 Participants

A purposive sample of 14 women from two cancer centres in the South of England who had undergone laparoscopic surgery in an endometrial cancer pathway, were given details of the study at follow-up. All those approached agreed to participate. The sample size is not predictable in studies using a qualitative approach such as phenomenological but it is likely to be small numbers, which allow for a greater depth of investigation (Sandelowski 1995). Completing the project depended upon the quality of the data from each participant and recruitment ceased when no new themes were identified, suggesting data saturation (Sandelowski 1995; Morse 2000). The mean age of the participants was 62 years (SD 11.5) and all except one were within a year of surgery. Six of the participants were obese to at least Class I (one had been refused surgery at another hospital because of her morbid obesity). Six participants were diabetic and eight lived alone.
14.6.4 Data Collection

Twelve participants chose to be interviewed at home and two preferred the hospital setting. The interviews took place between February 2008 and July 2009. The interview began with a single question asking participants to describe their experience of having the surgery. The reminder of the interview was led by the participant but maintaining the focus on the phenomenon and exploring themes as they emerged. The interviews were conducted by a single researcher (CH), lasted about an hour (mean 61 minutes; SD 14.8) and were taped and transcribed verbatim. Field notes and a reflective diary were also maintained as part of the audit trail.

14.6.5 Ethical Considerations

The study was approved by the Local Research Ethics Committee for both hospitals. An information sheet was given to the participants at least 24hrs prior to interview and written consent was obtained. The researcher was not involved in the clinical care of participants and contact details of clinical staff not involved in the research were available should the participants feel distressed by reflecting upon the experience. Care was taken to ensure participant identity was protected and pseudonyms have been used in the writing of this paper.

14.6.6 Data analysis

Colaizzi’s (1978) seven step framework supported the analysis (Table 1) and Microsoft Excel was used to organise the data. Colaizzi also described a preparatory phrase of self-reflection which involves the recognition of preconceptions and is in keeping with Heideggerian phenomenology. The researcher (CH) came from a background of gynaecological cancer nursing working
with laparoscopic and non-laparoscopic cancer surgeons. The self-reflection led to the development of a formal statement that represented the presuppositions about laparoscopic surgery for endometrial cancer which was used to guide the analysis.

14.6.7 Rigour

Phenomenology relies on the experience of the individual and the richness of the description that can be obtained, rather than generalisability (Streubert Speziale 2007). Data can be considered credible if others recognise the experience as one they have had or could have, which has been referred to as the phenomenological nod (van Manen 1990). However, steps were taken to enhance credibility which included supervision from an experienced interpretive researcher, the keeping of a research diary, using the participants own words in reporting the study and returning to the participants for validation of the analysis as the seventh step described by Colaizzi (1978).

14.7 Findings

Five main themes emerged from the data: having cancer, information and support, independence, normality and transfer of responsibility to the surgeon. These themes were used to create what Colaizzi (1978) described as the fundamental structure of the experience or phenomenological description.

14.7.1 Having Cancer

Although this study aimed to develop an understanding of laparoscopic surgery, the participants described having cancer as fundamentally shaping their experience because of fear associated with the disease. The fear of cancer was referred to directly and also in the avoidance of using the word, for example:
'I couldn't even say that word cancer...cancer, it frightens the life out of me' (Ellie) and 'I've always dreaded the word cancer, I think everybody does really' (Gail) and cancer is the 'missing' word in Betty's description of her diagnosis, 'they did call me back...they told, they told my daughter about, but they told, my daughter went with me and they say what I have but I suspect something like that before'.

Fear of cancer as 'a silent killer' (Betty) led participants to express their desire to remove the disease and feelings of having no choice about treatment, for example:

'all I wanted to do was get rid of it', 'it was cancer, I thought oh my God...I want it out, get rid of it, you know' (Ellie) and 'so if it was cancer, there was not much else I could do' 'basically you know if you've got a cancer you want it to be removed and so I had to have the surgery' (Mandy).

Although the participants were reassured when informed of the likelihood of being cured, the seriousness of the disease was ever present with thoughts of what could have been and what might be, for example:

'supposing I hadn't gone, what would have happened then?' (Ellie) and 'I've been more worried since, thinking it might come back' (Gail).

In England, government guidelines designed to improve cancer outcomes stipulate that all patients diagnosed with cancer should be treated within 31 days (DH 2000). Evidence of the impact of rapid treatment was identified in this study and it was described as both reassuring and frightening, for example:

'well it's all so scary but then they're getting it quick, aren't they?' (Jackie) and 'I was absolutely gob-smacked by that...perhaps I ought to have it really, really quickly' (Imogen).
14.7.2 Transfer of Responsibility to the Surgeon

The surgeon was described as the expert with the knowledge and skills to cure the cancer, even if the participant had experienced very little contact. This was reinforced by the referral process from specialist to super-specialist, for example:

'**my husband Googled (named surgeon), being in the top 200 surgeons**' (Christine) and '**(named surgeon) as he's the best laparoscopic surgeon anyway in the country**' (Helen).

The recognition of expertise formed part of the faith in the surgeon that was directly expressed by participants, for example:

'I had so much faith in him' 'he would do the right thing' 'he would do the best possible' (Alice) and 'I, I mean I, I just trusted him' (Frances).

There was a sense that surgeon embodied the success of the procedure and one participant, in the validation interview, clarified the interpretation of her faith in the surgeon by saying 'he saved my life' (Alice). The surgeon was seen as the one with the knowledge and skills to know what was best regarding the operation and taking passive role was alluded to by all of the participants, for example:

'it was his decision, he's the surgeon, you know' (Christine) and 'I just wanted to trust them and you know, they, I felt that I could trust them' (Mandy) and 'if they said jump through a ring of fire I would have done it' (Jackie) and 'I said I don’t care what you do as long as you get it out,' (Gail).

This was reinforced during the consent process when participants were informed that laparoscopic surgery may not be possible, only the surgeon could decide during
the operation. This also had the effect of making the surgery more desirable, only available if 'lucky' for which the participants became very grateful, for example:

'he said there's always a chance that you may not be able to have keyhole and that was, I thought, oh God, I hope I do have keyhole' (Jackie).

14.7.3 Information and support

Most participants referred to their lack of knowledge regarding cancer, surgery and the process of being in hospital, for example:

'you don't know much about cancer' (Christine) and 'but nobody in my family's ever had a hysterectomy at all, nobody' (Ellie) and 'none of the nurses at first said you know, got, told me what to do' (Frances).

Participants sought this information from the surgeon and the specialist team but did not want too much detail, for example:

'I didn't really want to know much, I didn't really want to know much about it, I think it was enough, it was enough for me, it starts to get you more and more worried, the basics or whatever I think that, that is important but I don't want to know anything else' (Katie).

However, it was the information regarding what would happen and what to expect that was described as lacking, with participants not being informed of the intravenous fluids, catheter or vaginal packing that they would have postoperatively, for example:

'I'd been told about the packing and I thought the girl in the (named) shop was having me on...I wish they'd told me, because I still thought she was having me on' (Jackie) and 'what's this? Tubes and oh, my God, what's all this' (Ellie).
The internet was mentioned as a possible source of information but it was also seen as unreliable or confusing, for example:

'you can get a lot of information, then your head can be feeling all jumbled with a lot of information and you can feel a bit confused really' (Mandy).

Information needs were individual and based upon prior knowledge and experience, for example Nancy 'just couldn’t read the books because (she) lost her mum to cancer'. Although participants had little experience of hysterectomy, there was a perception that open surgery as a bigger, more painful and debilitating operation. For example, when referring to another patient who had open surgery, Imogen referred to 'the terrible trauma of, of being, her body sliced open in two directions'.

As a result of these perceptions laparoscopic surgery was described as 'obviously' better, for example:

'but obviously it would be better to do it that way rather than having a big cut across the pelvis' 'why would anyone want to have something that hurts when they can have something that doesn’t?' (Katie).

Participants described how they had been supported through the experience by clinicians, family, friends, colleagues, the local community and the church but they also referred to their role in the lives and support of others, for example:

'My sister cried when she heard that it was cancer. I said don’t cry' (Dianne) and 'my daughter was shocked...childlike' (Betty).
14.7.4 Independence

This theme related becoming dependent on others because of illness and treatment and how independence was maintained and regained both physically and psychologically. Participants expressed a fear of dependency, especially those who lived alone, for example:

'all I was worried about, being on my own and not being able to cope because I've always sort of done me own thing all me life and I don't want to have to ....I would rather they gave me something' (Lianne).

Nurses provided care at times of most dependence and poor nursing was associated with a lack of 'caring' or 'nurturing' and the most important attributes of the nurses were described as 'kindness' and 'niceness'. Although most participants said they had few complaints about their care, the process of hospital treatment was considered mechanistic and not individualised, for example:

'I did feel as though I was on a conveyor belt' (Frances) and 'I mean we're just another, another, another person, aren't we to them, really' (Ellie).

There were references to the intimate nature of the illness and treatment, with comments about being dependent on the system and having no control regarding females doctors, female support and pelvic examinations, such as:

'everybody looking and talking to you and you feel embarrassed as well' 'I don't want to see anyone's face' (Helen) and one participant wake in recovery to find 'a man (male nurse) lifting up the bedclothes and the pad to see how much I was bleeding, I think that's wrong, totally wrong (Dianne).
However, the participants described being able to maintain a significant amount of independence with a low level of reliance upon others because they were able to care for themselves rapidly after the operation primarily due to mobility, for example:

"because I didn't need seeing to...I was sort of left to my own devices and happy to be so" (Christine) and "my friends are working and I think well if I'm walking around all right I don't want to bother (them)" (Jackie) and "you feel you're imposing, I don't want to have to depend on them" (Lianne).

14.7.5 Normality

Normality encompassed what was usual for the individual and how this was disrupted and regained. For most participants the disruption began with the return of vaginal bleeding or heavy bleeding, for example:

"I just couldn't even get up from my desk the bleeding was so heavy, um, and when I came home it continued to be heavy and I don't think I went to work the next day" (Mandy).

Participants described a loss of control and awareness of the body because of the bleeding and the cancer, for example:

"flippin glad that I went because you don't know, you just, you, you don't know that you're ill do you?" (Ellie) and "if it is still there, I don't know" (Helen).

The participants also described being altered by the experience, for example, Helen said, 'sometimes if you say it's a cancer, then everybody's looking at you differently' and participants described the difficulty telling other people, for example:
'I won't tell my husband' (Imogen) and 'I never sort of spoke like that to my husband so I'm sure I'm not going to talk to the kids like that, am I?' (Ellie) and 'I didn't tell my mother, I still haven't told my mother' (Katie).

Not appearing ill meant more control on who to tell and who not to tell and minimal scarring was described as creating disbelief that the surgery had ever happened, for example:

'that's it but and you've got nothing afterwards, nothing to, no stitching or no, all there is, is, like the, two, two little holes and like a line, that's all you've got' (Ellie) and 'you know I kept thinking have I dreamt it, or what, did they take...sometimes I haven't got a clue' (Nancy).

Three participants referred to the cosmetic appearance of the laparoscopic incision scars as unimportant for older women. However, for some participants even the small scars were a reminder of the cancer and the surgery, for example:

'unless I look in the mirror and, you know, I see it, I think oh God, you know, cover it up and remind me about it again in a few months when it's time to go (to clinic)' (Ellie).

Being in hospital affected normal bodily functions such as eating and drinking, bowel movements and sleep. Getting back to normality was important and there was sense of this happening relatively quickly, although there were some comments about feeling tired. Postoperative pain was primarily expressed as discomfort, for example:

'sore and uncomfortable to a certain extent' 'wouldn't say it was painful' (Alice) and 'I wouldn't say you were..., discomfort but not pain' (Lianne).
Of the seven participants in paid employment, some wanted time off regardless of feeling well, some described the difficulties of going back to work full time and one participant worked from home virtually on discharge from hospital.

14.8 Summary: Phenomenological Description

The fear and anxiety associated with having cancer shapes all aspects of the experience of having laparoscopic surgery for endometrial cancer. Trust is placed in the surgeon because of his/her knowledge and ability to perform a specialised procedure which can cure the cancer. Having cancer and having surgery removes the individual from the familiar and places them in a situation and environment that is unfamiliar and a transition is made to the world of the ill with loss of control, vulnerability and dependence on others. Flexibility, mobility and low levels of pain enable the individual to become independent rapidly after the operation and return to being well with few visible signs of being changed.

14.9 Discussion

Following data analysis the findings were connected to the literature and the practical application of the phenomenological description was considered in order to take 'what is' and go further to describe 'what might be' (Crotty 1996:7).

The findings of this study suggest that women with endometrial cancer undergo surgery in the shadow of the cancer diagnosis and fear of the disease is the context in which the experience is lived and interpreted. While it was not unexpected that having cancer would play a role, the significance of cancer on the surgical experience was underestimated given the high cure rates and relatively straightforward surgery which, in England, can be carried out in diagnostic units without referral into specialist cancer centres. Other phenomenological studies in cancer surgery echo this finding; Worster and Holmes (2008) and Mizuno et al.
(2007) set out to study the postoperative experience of colorectal cancer but discovered that participants chose to talk about the impact and burden of the cancer diagnosis and being constantly aware of having the disease. Bullen et al. (2009) identified the cancer journey as a theme representing the experience of penile cancer surgery and fear of cancer was identified as a theme following prostate cancer surgery (Powel & Clark 2005). Living in the shadow of cancer has been phenomenologically described as the omnipresence of cancer (Shaha & Cox 2003) and as cancer patientness which exists regardless of time since treatment or the presence of active disease (Little et al. 1998). However, this finding was not identified in any of the research on laparoscopic hysterectomy for endometrial cancer and is not just applicable to the laparoscopic route.

One of the most important issues for women in this study was the need to trust the surgeon. In England, the government is committed to empowering individuals with more choice and shared decision making in healthcare as outlined in the NHS Constitution (Department of Health 2009). However, the findings identified the difficulty having cancer has on the ability of the individual make complex choices with potentially life and death outcomes, where the chance of cure primarily rests on surgery and the skill of surgeon. Pellegrino (1981) suggests that because the ill person lacks the knowledge or skills and must seek the help of one with the ability to heal, this relationship will always be an unequal one, making shared decisions difficult to deliver.

The need to trust the skills and expertise of the doctor have been identified as things that matter to people with cancer (Burkitt Wright et al. 2004; Salkeld et al. 2004). The findings of this study also suggest that the concept of the surgeon may be equally important, given the limited contact with the surgeon identified by some
participants. Burkitt Wright et al. (2004) considered being a doctor as sufficient to communicate expertise but confidence can be increased when doctors are perceived as technically expert and acclaimed as reflected in this study. According to Luhmann (1979) society is so complex that individuals are forced to reduce complexity by using trust to obtain a feeling of control and trusting the surgeon as an individual or representative of a healthcare system can be seen as a way to reduce the complexity because the individual no longer has to consider the confusing alternatives (Giddens 1990).

Participants in this study adopted a passive role in decision making as described by Elkin et al. (2007) and Leydon et al. (2000). However, it has been argued that the decision to be passive should be considered a form of empowerment (Aujoulat et al. 2007). Mishel and Braden (1998) consider the transfer of responsibility to a ‘credible authority’ such as the surgeon, as a mechanism for empowerment, reducing uncertainty in illness by passing it to another. Choice and shared decision making in healthcare are not the only ways to empowerment and we may fail to offer individuals appropriate support if we do not recognising the dynamics of the relationship between a person with cancer in need of a life saving operation and the surgeon who can perform that operation.

Information needs were individual but participants described unmet needs focusing on being informed of what would happen, especially after the surgery and the practicalities of what to do and how to cope in an unfamiliar environment and situation. This type of information, associated with familiarisation and ‘knowing what to expect’ has been identified in preoperative preparation (Walker 2002). Providing this level of information can reduce aspects of uncertainty and by concentrating on
situations that can be controlled it is possible to gain a sense of security and reassurance (Aujoulat et al. 2007).

Women in this study described a fear of being dependent which has been associated with cancer (Toon 2007; Penson et al. 2005), especially those who lived alone. The majority of women with endometrial cancer are over 50 years of age and in Britain 30% of women aged 65 years are living alone, rising to 61% by the age of 75 (Office for National Statistics (ONS) 2009). However, low levels of pain and early mobility were described as contributing to self-care and a rapid return to control and independence which is important for independent living, especially in an older population and has been linked to positive psychological adjustment (Mishel et al. 1984).

According to Heidegger (1962), as humans existing in a world surrounded by other humans we feel the need to conform and become anxious if we stray too far from the norm, he called this *distantiality*. The impact of having cancer was described by participants as having the potential to make them stand out as different from others; different from whom they were before, being-in-the-world as a person with cancer. Having laparoscopic surgery minimised the externalisation of that change and gave the participants more control on who to tell and who not to tell by maintaining an exterior of normality.

**14.10 Conclusion**

Developments in the treatment of endometrial cancer offered a unique opportunity to study a new surgical technique from women who had undergone the procedure. The phenomenological description can be used to support the information given to women considering surgical treatment for the disease. The experience of laparoscopic surgery for endometrial cancer is complex and care
should be delivered which recognises the multifaceted dimensions of having surgery for cancer, including access to specialist support services. Acknowledging the role of the surgeon and providing information based upon familiarisation with the process of being in hospital and having surgery has the potential to empower by reducing uncertainty. Healthcare providers should consider treatments that offer reduced dependency on healthcare professionals, family and friends, promoting independence and maintaining normality.

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<thead>
<tr>
<th>Table 1. Colaizzi's (1978) seven steps of analysis</th>
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<tr>
<td>• Read all of the subjects descriptions</td>
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<tr>
<td>• Extract statements that pertain to the phenomenon</td>
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<tr>
<td>• Formulate meanings from these extracted significant statements</td>
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<td>• Organise formulated meanings into clusters of themes</td>
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<td>• Integrate the results so far into and exhaustive description</td>
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<td>• Formulate the exhaustive description into a statement of the fundamental structure of the phenomenon</td>
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<td>• Validate the findings with the subjects</td>
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14.11 Conflict of interest

None

14.12 Acknowledgements

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14.13 Author Contributions

CH, HA, WK were involved in the study conception and design. CH performed data collection and analysis under the supervision of HA. This study was part of a doctoral programme undertaken by CH with academic supervision from HA and WK.
14.14 References


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