Dignity and the child in hospital

by

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Abstract: Dignity and the Child in Hospital

This study makes an original contribution to the understanding of dignity and children in hospital. Despite theoretical deconstructions and empirical studies of dignity and adults (Nordenfelt and Edgar, 2005), there has been a dearth of theoretical or empirical work regarding dignity and children (Reed, et al, 2003). In response to this, I have taken an ethnographic approach to understanding the meaning of dignity by exploring and analyzing the perspectives of children, staff and parents on a hospital ward.

The main phase of the study took place over a nine-month period in a children’s ward of a District General Hospital. My main methods were participant observation and qualitative interview. During the fieldwork, I made observations on 97 children. In addition, I taped 31 qualitative interviews with children and their parents. 16 staff members gave interviews. I used principles from grounded theory to code responses and identify themes from data and reconstruct meaning through successive levels of abstraction to propose a theoretical framework.

Four factors were fundamental to the context of the study: the environment, power relations, the social construction of the children and the changing role of the nurses and parents in caring for a sick child in hospital. From my findings, I identified a dualism of the meaning of dignity, as something that is both intrinsic and extrinsic to the individual. Drawing from symbolic interactionism (Goffman, 1971), I describe how extrinsic dignity is performed using socially proscribed acts and rules and argue that dignity is “played out” on the body of the child. Dignity is important because of the intensity of emotions its loss provokes. I describe the emotional work involved in the promotion and production of dignity (Hochschild, 1983; Smith, 1992) and discuss the nature and role of the witness as influencing the experience of dignity. By placing children centre stage I have challenged the philosophical and theoretical notions of dignity as something acquired and dependent upon autonomy and bodily control. Dignity is a product of social interaction (Soyinka, 2004) where the macro analysis of dignity as the intrinsic worth of an individual is articulated through micro, socially proscribed acts of extrinsic dignity.
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Chapter One
Overview of the study

1.1 Introduction

Dignity has intrigued me throughout my nursing career. In this chapter I present a brief overview of my study, the aim of which was to explore the meaning of dignity for the child in hospital. In this introduction I provide a summary of the chapters of this thesis. I introduce the background of the research, in particular the competing explanations of the nature and meaning of dignity and the demonstrable absence of children from this discourse. I review the literature pertaining to these debates in Chapter One and in Chapter Two I describe my chosen methodology, that of ethnography and grounded theory. In Chapter Four I discuss the pilot work that set the trajectory and tone for the Main Study. In Chapters Five, Six and Seven, I discuss my findings from the perspectives of my self as researcher, the staff, and the children and their parents. In Chapter Eight, I discuss my findings and piece together the dimensions of dignity that resonate with children in hospital.

1.2 Background to the study

An investigation into the dignity of the child in hospital is timely. In recent times, there has been a proliferation of research into dignity and a commitment to the greater participation of children in social life. Rapid changes in the provision of health care for children have influenced the experience of hospitalization for children, with “one in ten to fifteen children admitted to hospital each year” (Department of Health, 2003; 1.5). In this study I aim to bring together these themes in an exploration of the meaning of dignity for children on a children’s ward.

1.3 A review of the literature

In Chapter Two, I describe my review of the literature. My initial literature searches in the late 1990’s led me to the theoretical discussions in the medico-nursing literature that were current at that time. Historical and philosophical (Lukes, 1973; Dworkin, 1993) explanations for the concept of dignity were proffered using an adult model. Conceptual
analyses suggested frameworks of understanding dignity in the context of health care (Mairis, 1994; Haddock, 1996; Shotton & Seedhouse, 1998). Empirical research concerning dignity has been more recent (Matiti & Trorey, 2004; Walsh & Kowanko, 2002), with much of the debate centred on the older person and their care (Jacelon, 2004; Nordenfelt & Edgar, 2005). My review highlighted a range of explanations of dignity that attempted to give coherence to disparate understandings of dignity. I found some of the writings that seemed most congruent to the meaning of dignity came from alternative literature (Montague, 1971; Levi, 1995). This review also brought into relief the absence from the research and literature of children and dignity.

In response to this omission I explored literature pertaining to the “child” primarily as a historical and social construct (Mayall, 1994; James, Jenks & Prout, 1998). My evaluation of policy demonstrated the growing visibility of children on the political agenda. In particular, I considered documents that have influenced the care and experiences of children in hospital (Report of the Platt Committee 1959; DoH, 1991; Audit Commission, 1993) and most recently, the National Service Framework for Children, and the associated publications (DH, 2003; 2004a; 2004b; 2004c). It was my exploration of research relating to the experiences of children and their families in hospital that revealed that despite a change in emphasis on the rights and well-being of children, in hospital, children were vulnerable. In particular I looked at studies that explored the subjective experiences of children and their families, including their lived experiences in hospital (Carnevale, 1997; Craig & Scambler, 2005; Noyes, 2000; Gasquoine, 2005). From this, the construction of disability alerted me to the stigma associated with individuals who fell outside the societal norm (Priestley, 1998; 2003). The absence of the child in the literature on dignity seemed to be a reflection of their marginal position in society and their relational position to adults. My exploration of the literature, to which I returned throughout the course of the research, is discussed in greater depth in Chapter Two. The process of the literature review dispelled any doubts that I may have had, that dignity was not important, or meaningful, when considering children and that a study investigating the meaning of dignity and the child was not only valid, but overdue.

1.4 Methodology
With these issues in mind I sought to understand the meaning of dignity for the child in the context of a hospital ward. The purpose of the study was to explore and understand the nature of dignity for the child in hospital. I aimed to capture the perspectives of the child, their parents and the staff and explore how dignity is experienced and expressed by the child. In Chapter Three I describe my methodology. Training and experience in counselling, influenced by the philosophy of Carl Rogers (1951; 1961; 1980), meant that I sought a methodology in keeping with the principles of person-centredness. Ethnography (Hammersley & Atkinson, 1995) allowed me to enter into the world of children in hospital. I sought to understand dignity and children by attending to the subjective. My approach was inductive and iterative with the concurrent analysis of the data influencing the direction of my research. Participant observation and interview seemed most appropriate with techniques to facilitate the participation of the children. Further reading and reviewing of the literature pertaining to research with children unearthed new and exciting approaches to involving children as participants (Greene & Hogan, 2005). My challenges in eliciting the voices of children served as data for understanding the controlling influence of my chosen context on both the children and my research.

I was attracted to the principles of grounded theory (Glaser and Strauss, 1967; Charmaz, 2006) as a way of approaching and analyzing my data whilst my fieldwork progressed. By comparing and drawing out themes from the data, I constructed categories representative of the experiences of children and their families and from these through successive levels of abstraction to theoretical interpretation.

1.5 Pilot work

I have included details of my pilot work in Chapter Four. This initial research was influential in the shape and trajectory of the main study. The scope of this preliminary work allowed me to observe children of different ages in different settings. My experience contributed to expanding my review of the literature in certain key areas namely: the body (Bendelow & Williams, 1998; Shilling, 2003) emotional labour (Hochschild, 1983; Smith, 1992), witnessing and stigma (Goffman, 1963;1971).

1.6 Findings
I have reported on my findings of the main study in Chapters Five, Six and Seven. In Chapter Five I reflect on my role as researcher. I have aimed to be reflexive throughout the study in keeping with the qualitative research tradition and also as a way of 'owning up' to my own feelings and choice of action (Kleinmann & Copp, 1993).

In Chapter Six, I have reported upon my findings from the staff. This includes data from observations as well as data from our interviews. I have structured my discussion around firstly the context and then, in Part Two, key themes that I drew out from the data. My analysis has been influenced by symbolic interactionism (Blumer, 1969; Goffman, 1971). Context included not only the physical environment, but also the changing role of the nurse and increased parental presence that resulted in a triadic relationship between child, parent and staff member. I describe the ways children were constructed in the hospital ward and make links between this construction and its influence on dignity. In the second part of the chapter I discuss meanings of dignity offered by staff. Areas of importance relating to an appreciation of dignity in the hospital environment include: the body, control and the impact of witnesses. I have incorporated extracts from our interviews that illustrate the thoughts and feelings the staff have in relation to their work and the families in their care. I describe some of their insights and assumptions about the children. I start to extrapolate from the data, a dualism of dignity that includes extrinsic and intrinsic dignity. I have adopted metaphors to demonstrate how the meaning of dignity is articulated through the performance of socially, and institutionally, proscribed acts, associated particularly with the management of the body.

In Chapter Seven I have reported on my findings from observations of, and interviews with, the children and their families. I have identified themes, corresponding with those from the staff in Chapter Six, but demonstrate the alternative perspectives of the child and parent participants. The strange environment had the effect of disempowering children and their families. This made them vulnerable to the demands of the staff, who themselves felt under pressure. I discuss how power differentials were played out on the management of the child's body from the legitimization of illness to the renegotiation of body boundaries. Parents described how they worked to ensure the best outcomes for their child, from passive acceptance to using anger. I explore the visceral connectedness
of parent and child and its implication for dignity. I describe the acute sensitivity of families, particularly those with chronic conditions and disability, to the unrelenting scrutiny of others, the witnesses on the ward. Whereas staff reflected on the practice of dignity, the children and their parents reflected on the experience. I have included verbatim quotes throughout the findings chapters as a way of "giving a voice" to the participants and to demonstrate the vivid and often emotional nature of their accounts. Children and parents appreciated an individual approach and I highlight instances when children felt acknowledged and valued. Above all they appreciated the sense of being recognized and treated as an individual and as one who mattered. For children and their parents, a successful performance of dignity involves emotions work and an articulation of the perceived humanness (by the staff member) of the other (the child).

1.7 Discussion and implications for policy and practice.

In my Discussion, in Chapter Eight, I bring together the streams of findings to offer an original perspective on the meaning for children in hospital. In this chapter I reflect on the impact of the context of the "strange" ward environment, the importance of the changing role of the children's nurse and the increasing presence of parents. I comment upon the impact of witnesses and the dependence of dignity upon witnesses. I explore the dualism of meaning of dignity, evident from the data, that of an intrinsic and an extrinsic dignity. I discuss the body as stage on which these meanings of dignity are played out and I describe how dignity is performed with the use of props and ritual. Dignity is important because of the intensity of emotion its loss provokes. I discuss how staff, parents and children alike manage their emotions to induce or suppress emotions in others and themselves. I discuss the legitimacy of some of the models of dignity described in the Literature Review and in so doing highlight something of the vulnerabilities associated with being a child. I demonstrate how my research contributes to knowledge regarding specifically dignity and the child in hospital and more generally.

I have also, in my discussion, highlighted areas that have implications for policy and practice. These are reproduced in appendix 12. In Chapter Nine, I have reflected upon the limitations of the study and make recommendations for further research. I end with a short summary of the research.
1.8 Concluding remarks to Chapter One

In conclusion I propose a model in which the principle of dignity as the intrinsic worth of an individual is articulated through the relationship to the performance of socially accepted and context dependent measures of extrinsic dignity. Fundamental to this relationship is the emotion work that confers the meaning of human value whilst attending to the bodily elements of extrinsic dignity. The relational position of children to adults in society renders them vulnerable to having their dignity overlooked.
Chapter Two

A Review of the Literature

2.1 Introduction to a Review of the Literature.

In keeping with the inductive approach of ethnography, my literature review was evolving and iterative. In this chapter I demonstrate the way my line of enquiry progressed as I moved from the literature to the field, to analysis and back to the literature, as I tried to understand my research area. This chapter is divided into two main sections, with subsections, that demonstrate the principal areas of literature I explored and illustrate my theoretical stance as I have progressed in the research.

I have represented the process of my literature review diagrammatically overleaf (figure 1). In this I demonstrate how the questions that have arisen for me from the literature, or the field, have prompted me to interrogate the literature of a particular area.

I have presented the literature review in what seems to reflect a linear progression, however this does not reflect the actual journey which was rather more zig-zag! By this I mean that as time and fieldwork progressed, I uncovered new areas of enquiry that needed to be interrogated further. The literature directed the initial investigations and, in turn, further reviewing of the literature was provoked by my experiences in the field. For reasons of clarity I have used sections to organize the material, in reality the areas overlap somewhat. Nevertheless, I have categorized the literature review into two main sections: 'The Meaning of Dignity' and 'The Child', with associated subsections.
Dignity and the Child in Hospital

Dignity

Dictionary definitions
Origins
Meanings

Alternative literature
The body
Medico-nursing

Dignity and dying
Older people

Empirical research
Experiences of children & their families in hospital

Political climate
Sociology of childhood

In a changing society
Meanings

The Child

Figure 1: Literature Review Mapping
2.2 What is dignity?

2.2.1 Dictionary definitions

Several definitions of dignity can be found in dictionaries. Some definitions explain dignity as a quality. One of the fuller examples with relevance to health care appears in the *Advanced Learners Dictionary* (1989). It defines dignity as a “quality that earns or deserves respect; true worth.” In a similar expression of dignity *Webster’s* (1976) offers “the quality or state of being worthy; intrinsic worth.” Both these examples are suggestive of dignity as an inner value. The *Oxford English Dictionary* (1989) also describes dignity as a quality, but does not make any inference to an intrinsic nature of dignity “The quality of being worthy or honourable, worthiness, worth, nobleness, excellence.” Alternatively dignity can mean “a composed manner or style” or “a sense of pride in oneself; self-respect” (*New Oxford Dictionary of English*, 1998). The definitions offered in *Collins English Dictionary: Complete and Unabridged* (2003) include “a formal stately or grave bearing”: “a state or quality of being worthy of honour”: “relative importance”: “sense of self importance” and “high rank”. These definitions, when applied to the context of the hospital environment and the inherent challenges to maintaining one’s self (Warren, et al 2000), seem not to apply. None of these definitions appear to encapsulate the variety of understandings of dignity relevant to vulnerable people without socially, or genetically, conferred rank. In particular they have little relevance to the child in hospital.

2.2.2 The origins of dignity.

As my research has progressed, so has my interest in the way meanings are socially constructed and the way concepts ebb and flow through time, both on a societal and individual level. This section provides an overview of some of the historical influences that have shaped the Western notion of human dignity. I discuss, briefly, the move from the importance of social position to the importance of the individual and the development of universal rights, pertinent to an understanding of dignity.

There seems to be some evidence to suggest that in past times, the sense of one’s own self-worth or dignity was linked with one’s social standing. The way one demonstrated one’s social standing was through an etiquette of manners. Elias (1978) illustrates this through his notes on the socially acceptable ways of attending to functions of the body.
including nose blowing in public. Whether it was "proper" behaviour to use a sleeve or a hankerchief, to sniff or to blow was dependent upon whether one was an agricultural labourer or lord.

The notion of the worth of an individual became internalized with the coming of the Enlightenment and the influences of the moral philosophies of Kant and Schiller (Jacoby, 1994). The intellectual period known as the "Enlightenment" is associated with the eighteenth century, but its roots go back further (Brians, 2000). Key themes of this period include the idea that human reason could overcome superstition, ignorance and targeted religion and hereditary aristocracy. The influential eighteenth century philosopher Immanuel Kant contrasted value with dignity, to emphasise that the intrinsic worth of persons ends in themselves and not merely as beings of instrumental value. An important change with regard to dignity is the move from obligations to rights and the rise in importance of the individual.

In his discussion of the origins of individualism, Lukes (1973, p.45) describes dignity as the "ultimate moral principle of the supreme and intrinsic value... of the individual human being". Christianity, and in particular the New Testament has been a powerful force behind the notion of the supreme worth of the individual. At other times, and within other cultures, the individual has had lesser significance. For example, Ullman, (1967) in The Individual and Society in the Middle Ages states that individuals were absorbed into their communities and society and cites collective punishment as an example of this.

This modern 'Western' individualism has, in turn, given rise to the idea of "natural rights". This egalitarian principle asserts that respect is due equally to all persons by virtue of the fact that they are persons (Lukes,1973). The philosopher Dworkin (1993) suggests that the modern concept of rights is based directly on the Kantian idea of human dignity.

The importance of human rights became widely recognized after the end of the Second World War. In 1948 the United Nations adopted the Universal Declaration of Human Rights (UDHR; Mann, 1999b). Rights are the entitlement of individuals and the denial of these rights is inconsistent with the ideal of human dignity. A central tenet of the Universal Declaration of Human Rights (1948) is that all human beings are born free and equal in rights and dignity. The restrictions of rights to children are arguably a reflection
of their position as incomplete persons. I shall discuss some of the policies and literature pertaining to the rights of children in section 2.3.3 “Children and the political climate”.

In the discourse of human rights, the notion of dignity has been translated into equality between persons. Mann et al (1999a) takes the discussion of dignity in human rights further and he describes a taxonomy of indignity. These violations of dignity are, arguably, applicable to the health care context. He describes a state of not being recognized or insufficiently recognized, being seen only as belonging as a member of a group, violation of personal space and humiliation.

A concept of dignity seems to be evident across cultures and global religions. Madan (1992, p.431) takes a transcultural view in his discussions of death and dignity:

"...across many cultures (and not only in Christian, Hindu and Jain cultural traditions) loss of autonomy, and loss of control over oneself in the context of death, are seen to result in an undignified death, that is death that lacks nobility, distinction and illustriousness."

Soyinka (2004) notes the saying of the Yoruba people from West Africa “Iku ya j’esin lo:” that translates to “Sooner Death, than Indignity,” has its equivalents in many cultures and "captures the essence of self-worth, the sheer integrity that animates the human spirit, and the ascription of equal membership of the human community." The loss of dignity in many cultures makes death mandatory. The Samurai warriors of Japan and Japanese soldiers of World War II took their own lives “to avoid falling into enemy hands, and to attenuate shame by Seppuku or hara-kiri (belly-cutting)” (Wikipaedia, 2007).

2.2.3 Meaning and usage of Dignity

It is apparent that not only the meaning, but the usage of dignity has evolved over time (Spiegelberg, 1971). Stetson, (1998, p.10) discusses dignity in relation to contemporary liberalism. He takes a political perspective in his discussion of dignity. He is critical of the way the term dignity is used “to underwrite the legitimacy of a wide range of public policy” initiatives on the basis that it has become aligned to the notions of self-esteem and rights in an era of moral relativism. He identifies two types of dignity: intrinsic and
Inherent, or intrinsic, dignity relates to "an absolute value" and he summarises the nature of human dignity in the following statement:

"All human beings...have full, equal, and constant intrinsic human dignity".

Extrinsic dignity he describes as not essential but contingent to the human person. It is a state that is earned by merit and differs from intrinsic dignity in that it is behavioral and tangible rather than theoretical and has some "historical and cultural relativity" (p. 17). It is evident from this statement that the vestiges of social value have not been eroded from the understanding of dignity altogether.

Other authors from a range of disciplines describe different types of dignity, suggesting that more than one type can coexist simultaneously. Jacobson (2007, p. 292) in her extensive exploration of "broader scholarship pertaining to dignity" makes this point when she attempts to synthesize a wide range of multidisciplinary writing from the areas of human rights, law, social justice, bioethics, care and health. She identifies intrinsic, that she calls human dignity and social dignity that subsumes all other types identified in the wider literature.

Sandman (2005, p. 45) in his discussion of a "dignified death" identifies a difference between "human dignity" and "dignity", that he later refers to as contingent dignity. The innate value of a human being as a person, he describes as "human dignity". He describes this as an evaluative claim that should guide the way persons are treated. Contingent dignity on the other hand, implies or bestows a high value to the bearer. He continues his discussion about "human dignity" in the wake of secularization, evolution and animal rights as "speciesism." In so doing he raises the question of whether other sentient beings, such as apes can claim a right to dignity. Meyer (2001) questions whether the concept of "human dignity" is morally disrespectful to nonhuman animals.

The requirement for an individual to be aware of their dignity to have dignity is debated widely in the philosophical arena. Dworkin (1993, p. 234) questions whether people suffering from dementia have the right to dignity if they have lost all sense of their own dignity. He concludes "...concern for their self respect does seem only sentimentality." I will return to this later when I discuss dignity and children. It is worth noting that others
argue as vehemently against this opinion, for example Sandman (2005) dismisses the need for autonomy or self consciousness as requirements for human dignity pointing to newborns and those with dementia and offers three alternative understandings of human dignity:

i) It is enough for not every single member of the human species to have autonomy and self consciousness, for human dignity to be associated with that species alone.

ii) It is enough for members to have the potential for these attributes.

iii) We could also include some of the so-called lower animals.

Contingent dignity he breaks down into dignity associated with controlled behaviour, aristocratic dignity based upon one's social standing and a dignity based upon being awe inspiring.

Sandman goes on to discuss the place of self esteem in dignity and proposes this conceptual understanding as having greater relevance when considering death with dignity, the focus of his book. His understanding of self esteem includes self determination, maintaining bodily integrity and having close relationships.

Wole Soyinka, the playwright and political activist, offered a different perspective and understanding of the interactional nature of dignity when invited to present the Reith lectures (2004). These annual lecture series have been broadcast since 1948 with the aim of "advancing public understanding and debate about significant contemporary issues". During his series entitled "Climate of Fear", Soyinka tries, in his own words, to "get to grip with the concept dignity". He questions why "...dignity appears to mean so much to the sentient human, almost right from childhood" He argues that compared to the other human needs "dignity may be deemed self-indulgent". He continues with an explanation of dignity that seems particularly pertinent to a health care environment:

"..it is within human relationships that the essence of a human attribute, such as dignity, is most meaningfully sought, not within the self as some mystic endowment, but as a product of social interaction" and "it (dignity) is manifested through the relations of one human being to another."
From this overview of the theories that underpin the notion of dignity, it is apparent that there are several meanings of dignity. Despite the recognition of inalienable human rights, there remains a debate concerning whether all of us are entitled to be treated with dignity.

2.2.4 The medico-nursing perspective on dignity

The apparent ambiguous nature of dignity led me to consider how dignity is understood within the medico-nursing literature that underpins the context of this research. My literature review in this subsection begins with the heart of nursing policy in the United Kingdom. The Code of Professional Conduct for the Nurse, Midwife and Health Visitor (1992) states that nurses must “recognise and respect the uniqueness and dignity of each patient and client”. This has been superceded by the Nursing and Midwifery Council’s Code of Professional Conduct: standards for conduct, performance and ethics (2004) which states in section 2.2: “you are personally accountable for ensuring that you promote and protect the interests and dignity of patients and clients.” Similarly in Guidance for Doctors (General Medical Council, 2006, para. 21(b)) doctors are urged to “treat patients with dignity”.

At the level of the institution, the hospital in which I undertook the research has as its second value displayed at the entrance to the hospital “We treat everyone with respect and dignity.” Therefore a clear and shared understanding of the concept of dignity is crucial for those who provide health care. Yet despite the urge to promote dignity in policies and guidance to health workers, the notion of dignity is left to the interpretation of the individual. Dignity is a slippery concept, difficult to define and most easily understood when it has been lost. A range of definitions of dignity can be found in the nursing literature (Mairis, 1994; Haddock, 1996; Shotton and Seedhouse, 1998) These tend to offer functional and reductionist definitions, to enable dignity to be implemented practically and are not empirically based. Numerous research studies endorse the need to promote and maintain dignity. No doubt because of the confusion about the term relevant empirical work has concentrated traditionally on the examination of related psychological concepts such as respect, the self, self perception and self esteem (Harter and Pike, 1984) There is a lack of information about the construct dignity in the literature and in particular how dignity is perceived, experienced by and respected in the child (Reed, et al 2003).
Attempts to deconstruct the concept of dignity have been the subject of three nursing papers (Mairis, 1994; Haddock, 1996; Shotton and Seedhouse, 1998). Each paper has concentrated on the adult and each has reached differing conclusions with regard to the nature of dignity. Mairis (1994) states that dignity is said to exist where the individual is:

"capable of exerting control or choice over his or her behaviour, surroundings and the way he or she is treated by others. He or she should be capable of understanding information and making decisions. He or she should feel comfortable with his or her physical and psychosocial status quo."

Her analysis is dependent on the patient being aware of their situation with the potential for asserting choice. Haddock (1996, p.930) uses a similar method of conceptual analysis as Mairis to analyse dignity, but describes the concept rather differently:

"Dignity is a dynamic subjective belief but also has a shared meaning among humanity...its maintenance depends on one's ability to keep intact the boundary containing beliefs about oneself and the extent of the threat."

She goes on to say that disintegration of this boundary, leads "to feelings of worthlessness " (p. 927). In her conclusion Haddock states:

"The most powerful tool a nurse possesses to maintain and promote dignity is herself, to work with feelings, use them constructively to understand patients, and to try to treat them as valid, worthy and important at a time when they are vulnerable."

Haddock's analysis of dignity concentrates upon the psychodynamic relationship of nurse and patient.

Shotton and Seedhouse (1998) take a different approach, leading to a more functional and arguably reductionist way of understanding the concept:

"A person will have dignity if he or she is in a situation where his or her capabilities can be effectively applied."

In a more recent paper, Gallagher (2004) argues that dignity can be considered subjectively and objectively, something that is both self-assessed and something that
can be bestowed on by others. Dignity can be a non-changing quality and also experienced as a matter of degree.

The activity of concept analysis for the purpose of engendering a greater understanding of a concept such as dignity has itself attracted criticism and debate. Paley (1996) states that concept analysis can be reduced to an argument over semantics, rather than a starting point for operationalization of a concept and subsequent theory generation. Thorne, (2005) agrees that abstract analysis is restrictive, she states:

"Our theoretical project ought to be motivated toward the goal of deeper reflection and expanded critical interpretation, not defining, constraining or concretizing ideas" (Thorne, 2005, p. 107).

In order to define and provide a measuring instrument for health practitioners, the Department of Health (2001) produced in their series “Essence of Care”, benchmarks relating to privacy and dignity. Dignity was defined as “being worthy of respect” for the purposes of this guidance and privacy as “freedom from intrusion.” These benchmarks were designed as way for staff to audit a health care setting in relation to a number of quality standards as part of clinical governance and best practice.

The frustration of trying to conceptualize dignity out of context has led others to dispatch with it all together. Macklin (2003) is derisive about the term dignity and its ambiguity and argues that it could as well be replaced with the principle of respect for autonomy. She is particularly critical of the usage of the term dignity in bioethics and, as a professor of medical ethics, does not refer to its relevance to health care. Her frustration with dignity appears, to be due to the apparent lack of objective criteria to validate dignity. Macklin acknowledges the influence of religion on the adoption of the concept of dignity in medicine “especially but not exclusively in Roman Catholic writings” (p.1420). However, she is puzzled how this "has let dignity creep into the secular literature in medical ethics." In particular, Macklin does not discuss dignity in relation to children for whom her preferred principle of “respect for autonomy,” I argue, is equally as questionable. Her rebuttal of dignity in the *British Medical Journal* attracted an outcry from the profession who came to the aid of dignity with a range of definitions and anecdotes in support of its usage (bmj.com, 2004).
Dignity therefore is still in favour, but remains difficult to express. It is interesting to note that the association of dignity with privacy is noticeable only when one moves from the general to the more specific health related texts. The overlap of privacy to dignity is apparent in the two following definitions of privacy. Woogara (2005) argues that privacy, in the hospital context has two forms: privacy of information and privacy of the person. Similarly, Charles-Edwards (2005) discusses privacy in terms of what it means for children’s nurses by defining three ways in which privacy can be understood: physical dignity, privacy of information and family privacy. Similarly the staff participants in the study tended to equate dignity with privacy (6.6.1.2). Here again the challenge of defining operationalising and measuring dignity in a meaningful way has led to dignity being substituted with privacy and other constructs, both in the research literature and in practice.

2.2.5 Empirical studies exploring dignity

Despite raising interesting issues in relation to dignity, of greater relevance and meaning have been studies that have explored dignity in a given context and based upon empirical work.

One of the few studies relating to dignity and children, a study by Rylance (1999), has confirmed that privacy and dignity are not always respected on children’s wards. Rylance undertook a structured questionnaire with the parents of 300 child in-patients to assess how well privacy, confidentiality and dignity were respected on the ward. He concludes that although ward design is important, lack of respect for patient’s dignity, breaches of confidentiality and privacy were problems of behaviour, attitude and lack of thought. Despite identifying the need for empirical work, dignity is not addressed as a central concept and the focus of the work is on privacy and confidentiality. Without a clear understanding of dignity in the child, based on empirical work, it is impossible to appreciate fully the concept from the perspective of the child.

The acknowledgment of the applicability of qualitative methodologies to healthcare (Mays & Pope, 1995) and nursing in particular, has enabled researchers to approach the empirical study of dignity in a different way. In recent years, naturalistic research approaches rather than experimental designs with an emphasis on the subjective
experiences of participants have offered an alternative and inductive approach to understanding dignity. One example of this approach to the study of dignity has been the small phenomenological study by Walsh and Kowanko (2002) to uncover the perceptions of dignity held by nurses and adult patients. Walsh and Kowanko noted the "many and varied" meanings of dignity ascribed by the nurses. Important elements included respect, privacy, control, advocacy and time. Themes arising from the patient responses were similar and included respect, privacy, control, choice, humour and matter-of-factness. They concluded that although perceptions of the two groups were similar, compromises of dignity still occurred. The patients responded with more affective responses to their understanding of dignity compared with the nurses who offered more objective meanings.

An example of larger scale empirical work undertaken in a range of hospital settings is described by Matiti and Trorey (2004). They interviewed 102 patients, men and women over the age of sixteen from three hospitals and from different specialities. In their summary of findings they discuss self and worth in relation to dignity as well as in relation to a "set of standards" that have been learned. They conclude that patients necessarily make "perceptual adjustments" to what constitutes proper maintenance of their dignity. Patients cope by suspending dignity, in a hospital environment and submitting themselves to the health care workers who hold "expert power". They do not attempt to suggest a working definition due to the complexity of the phenomenon.

The two areas of practice that have dominated empirical work with regard to dignity have been Dignity and Older People and Palliative Care

2.2.5.1 Older People and dignity

The experience of older people in relation to dignity has attracted debate at the level of the media (Wilson, 1999) and health and social care research. In an attempt to redress the lack of dignity felt and reported by older people in NHS care, Help the Aged forged their "Dignity on the Ward" campaign (1999). They, together with the Royal College of Nursing, called for targets to be set to cover, amongst other measures, dignity. The campaign was not to understand dignity but to identify and stamp out the causes of loss of dignity. Over 1000 letters were received from older people and their relative
documenting their negative experiences of hospital care. Amongst other recommendations, the Policy Statement (2001) report called for improving attitudes to older people, suggesting that negative stereotyping of an individual is likely to cause a detrimental effect upon their dignity.

An exploration of some of the issues surrounding dignity and older people reveals similarities to the dilemmas relating to dignity and children, notably the vulnerability associated with lack of bodily autonomy and reliance on others. Pullman (1999) argues against the association of dignity with autonomy and its relevance to the long term care of older people. He suggests that by equating dignity with autonomy, there is an implicit danger of assuming that people who lack the capacity for autonomous choice also lack human dignity. He too goes on to distinguish between two types of dignity: "basic dignity" and a socially constructed "personal dignity."

Further to his earlier work, Seedhouse has undertaken some pilot work with Ann Gallagher (Seedhouse & Gallagher, 2002) based on the care of older people to develop work on dignity. They used interview, an observation tool and an attitude scale to gather data on staff responses. Nine patients and seven relatives also took part across three sites. Their research was designed primarily to find out "What does dignity mean to you?" What factors promote or enhance dignity on the unit/ward? What factors make maintaining dignity difficult? They draw out the need for respect and the need for individuals to be recognized for their common humanity. Although their work is based on older people the transition of dignity through the lifespan is not explored. For children respecting dignity is not about denying the person who they once were, but denying who they could become. As discussed (2.2.2), a Kantian perspective would argue that all humans have natural rights because they are human. This value is reflected in this study. Seedhouse and Gallagher (2002) state that respect is a key concept in dignity and that this amounted to a "recognition of patient's common humanity, whatever their illness, status, age or race."

An important contribution towards the understanding of dignity in relation to older people has been the "Four notions of dignity" as described by Nordenfelt and Edgar (2005) as part of the Dignity and Older Europeans programme. These four notions are: dignity as merit, dignity of moral stature, dignity of identity and Menschenwürde. Dignity of merit
refers to the dignity of high rank bestowed on those of high social standing, through birth or attainment. Dignity as moral stature is dependent upon the thoughts and deeds of the individual tied into self respect. Dignity of identity is described as the concept “most vulnerable to the actions of others” (Bayer et al. 2005, p.22). Dignity of identity takes into account our relationships with others” and “persons with a history and persons with a future” (Nordenfelt and Edgar, 2005, p.19). Menschenwurde, refers to a dignity that all humans have, or are assumed to have because they are human. These notions were drawn from an extensive empirical work that included a review of philosophical and professional literature from which this theoretical account of human dignity was developed. This was later tested during empirical work including focus groups with older people, health and social care professionals and younger adults. The third phase of the programme included refining the theory and the development of educational resources and policy recommendations. The project group was multi disciplinary with eight partners from six European countries. The programme concentrated only on the dignity of older people and did not challenge the adaptability of the model by seeking to apply it to persons at the other end of the life course from the participants in their study, children.

Alternative analyses of dignity have been offered by Jacelon et al, (2004). The rationale for this study was to “provide a theoretical basis for nurses to develop interventions that foster dignity for older people” (p.76). They deconstruct human dignity in an attempt to clarify the meaning of dignity in treatment and also in death for older people. They undertook a review of the literature from the USA, Canada and Great Britain and five focus groups with older people in the United States. They summarise:

“Dignity is an inherent characteristic of being human, it can be subjectively felt as an attribute of the self, and is made manifest through behaviours that demonstrate respect for self and others” (Jacelon, et al, 2004, p.82).

They do not debate the apparent contradiction when they also conclude:

“Dignity must be learned, and an individual’s dignity is affected by the treatment received from others” (Jacelon, et al. 2004, p.76).

From their literature review and focus groups, the data were organized into the four themes of: philosophical, attribution, behavioural, and developmental. The developmental aspect was not uncovered in the literature but dignity was identified by
the focus groups as a learned behaviour leading the authors to conclude that "learning about dignity was an antecedent to behaving with dignity" (p.81).

Chochinov et al (2002) describes an intervention for dignity preservation for use with older people – a notion that dignity is linked to their legacy, that something of the essence of the individual lives and will live on even beyond death. Chochinov's research and others exploring dignity and older people have constituted the most thorough empirical studies on dignity. Yet explanations based upon merit, learning and legacy are less valid when contemplating the meaning of dignity to the young.

2.2.5.2 Dignity and dying

Dignity has become synonymous with "death with dignity" as debated in the media and as a theme of discourse in the literature (Madan, 1992). Sampaio (1992, p.422) states that guidelines for practitioners "must be based on never losing sight of the fact that their basic 'raison d'etre' is not to leave the helpless in their misery." Several authors discuss dignity and dying in the palliative care setting. Chochinov et al (2002) propose a model based upon empirical research with people nearing death. They used semi structured interviews to determine how the respondents understood and defined dignity. Three categories emerged: "illness related concerns", "dignity conserving repertoire" and "social dignity inventory". Within each category were sub-themes. The authors explored, with the respondents, whether they thought that dignity was something that was intrinsically held or something that was externally bestowed or withdrawn. Of the respondents who were outpatients, nearly all endorsed an internally held notion of dignity whereas of the in-patient cohort, nearly two thirds expressed the view that dignity could be taken away by others. The authors acknowledge that the sample in this study was of terminally ill cancer patients, usually older people and therefore warn against the generalizability of their findings. However they conclude:

"patients who are cared for in hospitals or other institutional settings are more vulnerable than out patients to experiencing a fractured sense of dignity" (p.440).

The literature concerning palliative care includes concepts and constructs that are relevant to dignity such as privacy. As I have discussed, (2.2.4) throughout the medico-
nursing literature, and the nursing literature in particular, there is an association between dignity and privacy. Sometimes these terms are used interchangeably. The nature and meaning of privacy in palliative care is discussed by Street and Love (2005) and it is in this paper that the involvement of the two concepts with one another is most noticeable. Their review of the literature reveals privacy to be both a way of managing difficult symptoms and allaying shame and stigma and also to protect others from distressing sights and smells. Their analysis of attitudes and practices of ninety health care staff regarding privacy and palliative care led them to promote “an understanding of privacy as containing spatial, psycho-social and moral dimensions” (p. 1803). They acknowledge and argue against the use of privacy as “unnecessary concealment.”

This idea of protecting through “sequestration” of the afflicted is highlighted by Lawton (1998; 2000) in her vivid ethnographic study of day and hospice care. Lawton (2000) argues that: “a significant proportion of patients are admitted to hospices because of the way in which their disease spread” and how this had affected the boundedness of their bodies, undermining their identities as persons. Her discussion reveals a disgust and shame associated with the disintegration of bodies and the sequestration of unbounded persons to the confines of hospices.

The direction of the literature search extended into the care of older people and the dying as more literature was available about dignity in these contexts. In addition, these areas provided a contrasting perspective on the concept of dignity as it might relate to children. The dilemma expressed in the literature concerning the appropriate and “dignified” way to treat the aged, infirm and the dying brings me to discuss the sociological discourse concerning the body.

2.2.6 Dignity and the Body

The care and management of a body by oneself and others provides the focus of discussion around dignity in a number of papers and media (Lawler, 1991). Indeed the concern with privacy as cited in the medico-nursing literature, seems largely to be based upon the need to cover and protect the body from exposures. Physically the body contains the person and the skin provides the interface between that which is inside (intrinsic) and that which is outside, extrinsic. It is the vehicle in which the individual
exists and interacts from in the world. For this reason I searched some of the literature relating to the body. In particular I was interested by some of the perspectives from social anthropology and the social construction of the body (Williams and Bendelow, 1996; 1998; Bendelow and Williams, 1998).

Western medicine has been influenced by ideas of Mind - body dualism central to the philosophy of Descartes. With mind and body separate in this way 'I' exist in pure consciousness with my body existing as part of the external world. Williams and Bendelow (1996, p. 26) argue that "Western medicine has, traditionally speaking, shown little interest in what may be termed the 'lived' as opposed to the 'objective' body" and continue:

"Indeed, it would not be too much of an exaggeration to say that medicine, in large part, operates with a peculiarly 'dis-embodied' approach to the patient" (p.26).

In her research, Lawler (1991) places the body central to her study of the work of nurses. Much of this body work described by Lawler concerns the management of out of control bodies. She calls this "dirty work" because it "concerns privatized bodily functions" (1991, p.121). Lawler links her work back to that of Douglas (1991) who identified an uniformity across cultures for pollution management systems as a means of dealing with body dirt. Lawler’s study, using ethnomethodology and grounded theory, was commenced in 1985 when an essential component of the work of nurses was the management and control of patient’s bodies when they were unable to attend to them themselves.

The importance of bodily control and its relationship to dignity was evident in the literature. Lawton (1998; 2000) in her ethnographic study of hospice care argues that the western concept of selfhood, or "person-hood," is dependent upon the notions of "corporeal self-containment" and the capacity for mobility.

From a theoretical point of view, Littlewood (1991, p.174) makes a link between excreta and control. "If the boundary we have drawn between ourselves and the outside world breaks down, we find it profoundly disturbing." She discusses the shame and humiliation associated with loss of control and dirtiness of excreta. Incontinence can reduce one to a
childlike state she continues. This reference to children infers a lesser position of children that begs the questions: What of children? And what does this say about children and their state?

I explored some of the ways the body becomes the focus for the maintenance and promotion of dignity. The body and its meanings are culturally bound. Littlewood (1991) suggests that meanings, that is cultural meanings, are put upon both the structure and the functions of the body. She argues that, from birth, the child is subjected to constraints upon his or her body. She borrows the notion of scaffolding as the way a mother acts for her child through possessing the cultural blueprints through which the child must organize his (or her) life, and linguistics. Littlewood cites the work of Vygotsky (1896-1934), the developmental psychologist, when she argues that through social interaction, these blueprints become internalized. In this way the mother may possess the cultural blueprint for what is deemed to be dignity in a given culture.

Disability studies offer a critical perspective on the management of the body in contemporary medicine. My research is placed within a health care setting and within the position of modern medicine that deems that illness and disability can be controlled. Wendell (1989) is critical of this stance and suggests an alternative feminist theory of disability when she describes her own experiences of a disabled woman. Wendell describes the way health and vigour are perceived as moral virtues and the disabled are stigmatized. She says that in a culture which loves the idea that the body can be controlled, those who cannot control their bodies are seen (and may see themselves) as failures.

To have dignity is to have control over oneself, particularly bodily functions. Mitteness and Barker (1995) highlight the shamefulfulness of incontinence and the normalising strategies incontinent people adopt to cope with incontinence. Mitteness and Barker argue that incontinence is linked culturally to incompetence and state that control of oneself and one's environment is a requisite for adult life.

Incontinence is stigmatised early in life. Ludman and Spitz (1996) detail their research into the psychological effects of faecal incontinence on the lives of young people aged
between six and eighteen years of age. They describe the children's "deviousness" and strategies for concealment and coping.

The nurse's role in containment has been discussed widely, both in terms of space and time. Littlewood (1991, p.177) describes the nurse as a "mediator of pollution". The nurse's role is to "become intimately involved and identified with the control of personal pollution" (p.178). Nurses use curtains to delineate and contain the personal space of the patient and protect patients when they are in the ambiguous state of ill health. This containment is not just bodily pollutants but also uncontrolled emotions, which can be a threat to the dignity of an individual. The notion of control, particularly self-control, is central to the maintenance of dignity. Littlewood (1991) acknowledges the potential power of the nurse and states: "The nurse can... use humiliation as a tactic of control" (p.184).

From a psychoanalytic perspective, Jacobs (1995) describes the work of Winnicott (1896-1971) the child psychotherapist who describes the skin as a "limiting membrane" which acts as a type of container. Winnicott uses the image of a bubble, where the pressure inside is equal to the pressure outside to describe the state of "being". Continuity of this being is health, but where there is some impingement from outside continuity of existence is interrupted. These ideas have parallels with the Freudian psychoanalyst Anzieu (1990) who describes the skin as a membrane which makes contact with the outer world and as a boundary for the inner world as a psychic envelope.

Place (2000) undertook an observational study of a Paediatric Intensive Care Unit (PICU). He recorded the nurses interacting with the machines that maintain the child and their body. He questions the definition of the child's body: "What exactly are the corporeal elements of a child's body that are open to negotiation?"(p.172). He describes the ambiguity of the physical boundaries of the child's body. Place states that products of the PICU such as the vital signs observation chart is used to order and textualise externally the critically ill body of the child. In his ethnographic study he suggests that observation chart not only represents the child's body but gives the body a greater visibility to those who are trying to understand what is going on and care for the child:
"Every child's body, regarded as a unique entity outside the intensive care unit is, regardless of size, age, gender, colour and illness made to 'fit' into this space" (p.177).

Place takes a term coined by the nurses in the study “sorted out” and translates it to mean sorted – ordered and out-externalised. He describes the PICU as a liminal space in which the children consist of both “'soft' human flesh and 'hard' technological artefact” (p.174). It seems here that the individual child is lost to view:

"The clinical gaze of the nurse moves away from the corporeal body of the child toward those devices that represent that corporeality" (p.177).

Place does not, in this account, discuss the presence of the parent and the child disappears without their apparent input. Place, as ethnographer, seems distanced too by this representation of the child. His clever analysis seems dichotomous to the subjective realities of the children themselves who are unable to offer their experiences. Place goes on to describe:

"the cannulation, intubation, catheterisation and the insertion of artifacts into the inside and on to the surface of the corporeal body" (p.175).

The integrity of the body boundary is broken. This assault to bodily integrity can be seen as a compromise to dignity.

James (2000) is critical of the absence from literature of children as embodied beings and the lack of the experiences of children as they undergo rapid bodily change as they mature. An exception to this is the research of Craig and Scambler (2005) who describe the stigmatizing effects of tubes, in their study naso-gastric tubes, that signaled difference. Goffman (1963) provides an analysis of stigma as spoiled identity, a discrepancy between virtual and actual social identity (Williams and Bendelow, 1998). Goffman (1963) describes features such as naso-gastric tubes as stigma symbols signally difference. Craig and Scambler use Goffman’s analysis to describe the felt stigma or courtesy stigma of the parents of disabled children described in their accounts as “the perceived negative reactions of the public, usually in the form of hostile staring or unwelcome questioning” (Craig and Scambler, 2005, p.6). They conclude that:
“Children’s bodies that fail to conform reflect badly on women’s parenting skills and render children outside the culture” (p.8).

In her ethnographic study of a hospice, Lawton (1998, p.107) describes the way hospice patients undergo a change in their self-perceptions as their bodies weaken and deteriorate, from that of subject to object. She suggests that this is compounded by a further “objectification” of them by those involved in their care. She describes a woman in the end stages of her disease who, when admitted to the ward was not connected to her electronic feeding device until the morning following her admission. A discussion ensued between the husband and staff about whether it might be better if she were to lose weight, to enable him to manage her better at home. The centrality of the patients dependent body, Lawton suggests excludes any possibility of the patient being seen as a social person.

The work of nurses extends to the care and management of the unconscious and dead bodies. The importance of promoting dignity in this work is discussed by Meerabeau and Page (1998) who undertook ethnographic work on the management of cardiac arrests by nursing staff. Meerabeau and Page cite the work of Mairis (1994) when they state that:

“the concept of dignity, although generally poorly clarified, assumes great importance in the delivery of care, especially when people are helpless or unconscious.”

In a socially constructed world, where nurses are expected to know what to do with the unconscious and the dying they are afforded special authority. Whether dignity assumes a greater significance when caring for the unconscious is debatable. Meerabeau and Page (1998, p.307) state:

"The felt need to show respect means that the situation and the body are handled with dignity and seriousness."

Thus although dignity may have been lost in the process of dying it may be retrieved in death via appropriate actions and the assumption of “suitable emotions." I would argue that the dignity is merely suspended, that although the body might be handled roughly and disrespectfully the intrinsic dignity of that person is not lost and the final rituals of the last offices are the socially proscribed performance of dignity.
2.2.7 Emotion work

My review of the literature surrounding emotions took place towards the end of the research. In my struggles to understand dignity I overlooked that dignity was important because of the powerful emotions the loss of dignity evoked in individuals and those around them. Williams and Bendelow (1996) note the absence of emotions in the medical literature generally and argue:

"... emotions provide the 'missing link' in (medical) sociology between mind and body, inside and outside, structure and agency, micro and macro, public and private, and a host of other dichotomous ways of thinking" (p.37).

Hochschild (1983) describes the emotional work of those working in the service industry. Her study of flight attendants, led her to offer an explanation of how people manage their feelings and use their emotions in their work, for example to generate a feeling in another. Her ideas were used subsequently in research into nursing (James, 1989: Smith, 1992). In particular, Smith (1992) describes the influence of the ward sister or charge nurse in determining 'feeling rules' thereby setting the emotional climate of the ward (Smith, 1992).

Lawler (1991, p.126) describes the centrality of emotions management to nursing. She suggests managing emotions is all part of the "professional approach" of the nurse. Lawler describes "learning how to do body care and perform their nursing functions in a manner typical of the occupation" is important to student nurses.

2.2.8 Non-technical literature

Strauss and Corbin (1989) identify two types of literature to be used in research, technical and non-technical. The technical literature is limited if one stays within a medico-nursing texts, which is subject and context specific, yet vast if I am to consider dignity as a concept that runs through many philosophical and theoretical frameworks. On exploring and interpreting the non-technical literature I was able to appreciate, more fully the meaning of dignity. Below I have included an extract from Primo Levi's autobiographical account of the process of assimilation into the concentration camp, Auschwitz and the effect on the self. In this example, Primo Levi (1995, p.33) gives a
graphic description of political manipulation and its impact on institutions and individual's sense of self.

"Nothing belongs to us anymore; they have taken away our clothes, our shoes, even our hair; if we speak, they will not listen to us, and if they listen, they will not understand. They will even take away our name; and if we want to keep it, we will have to find ourselves the strength to do so, to manage somehow so that behind the name something of us, of us as we were, still remains.

We know that we will have difficulty being understood, and this is as it should be. But consider what value, what meaning is enclosed even in the smallest of our daily habits, in the hundred possessions which even the poorest beggar owns: a handkerchief, an old letter, the photo of a cherished person. These things are part of us, almost like limbs of our body; nor is it conceivable that we can be deprived of them in our world, for we immediately find others to substitute the old ones, other objects which are ours in their personification and evocation of our memories.

Imagine now a man who is deprived of everyone he loves, and at the same time of his house, his habits, his clothes, in short, of everything he possesses: he will be a hollow man reduced to suffering and needs, forgetful of dignity and restraint, for he who loses all often easily loses himself”.

As Primo Levi suggests one’s identity has to do with one’s possessions, habits and the way we present ourselves to the world. This in turn is enmeshed with our sense of dignity. The way children are allowed to present themselves is controlled (see the later chapter where I review 2.3.2 Sociology of childhood) and arguably, no more so than when they are admitted to hospital and they give up their normal clothes, activities and often possessions as they are expected to “fit in” to the ward restraints.

The social nature of dignity suggests that loss of dignity and resultant humiliation, cannot occur in isolation - it needs the presence of others. This is expressed poignantly in the story of John Merrick, known as the Elephant Man, paraded as a monstrosity and object of loathing. His overwhelming degradation resulted in him pleading to go to a blind asylum or to a lighthouse. He died when he tried to lie down in the manner of other people (Montague, 1971).
Using other texts such as newspapers gives an interesting and current flavour of why
dignity is important to people. There has been considerable press coverage about
hospitals in Britain and a certain outrage at the way people are treated. The care of older
people has been the focus of a great deal of this attack and the "Dignity on the Ward"
campaign ensued backed by Help the Aged. No such campaign has been launched for
children, presumably because they are not considered so neglected in hospitals. Where
children have featured in the media coverage has been through the reporting of the
Alder Hey Hospital’s retention of body organs following the deaths of children and
without the consent of parents. The focus of these reports has been the grief of the
parents rather than the violation of the bodies of the children albeit after they had died
(BBC News, 2001). Similarly reports of the poor results of paediatric cardiac surgery at
Bristol Hospital have focused on the distress of the parents, the ethical issues of the
attending staff and malpractice (Butler, 2002). The focus has been upon the
consequences to the adults, rather than to the children.

2.2.9 Concluding comments to “What is dignity?”

In conclusion, there have been numerous attempts to clarify the notion of dignity from a
range of perspectives and from different methods including empirical research. A
distinction is commonly made between an intrinsic dignity: Menschenwurde (Nordenfelt
and Edgar, 2005), basic dignity, personal dignity of the type referred to in the Universal
Declaration of Human Rights (1948) and a variable notion of dignity referred to as
extrinsic or social dignity. In addition an interactional meaning of dignity has been
proposed (Soyinka, 2004).

I have discussed some of the literature pertaining to the sociology of the body (Lawler,
of the body and the experience of embodiment is key to understanding the meaning of
dignity. The body provides the platform on which dignity is given meaning and is played
out. Some of the literature concerning the sociology of emotions (Hochschild, 1983;
Smith, 1992) and symbolic interactionism (Goffman, 1963; Benzies and Allen, 2001)
contributes to understanding how this is achieved.

Of particular importance in exploring dignity empirically has been the research
undertaken in the context of older people and the resulting discourse. The societal
position of older people has some similarities with that of children and their experiences at the other end of the age continuum can offer a contrasting perspective.

The palpable lack of research relating to dignity and children (Reed, et al, 2003) suggests that dignity is not a concept widely associated with children. Exploration of dignity with regard to children could be used to verify the emergent theories discussed above, concerning the meaning of dignity as well as the applicability of theoretical frameworks across the life span. More important than this, and the focus of this thesis, is the meaning of dignity for children in hospital and the meaning of dignity for their parents and staff on the ward.

Having researched dignity it was essential to investigate the meaning of 'The Child' and children from the literature in a similar vein before moving on to consider an appropriate and fitting methodology.

2.3 The Child

2.3.1. Children in a changing society

In attempting to understand the meaning of dignity for children in hospital, I explored the everyday meaning of children in society. This section includes literature from a theoretical perspective and empirical research that have influenced the choice of approach in my own fieldwork.

Akin to the concept of dignity, children and childhood have also undergone an evolution of meaning in society (Aries, 1996; Cunningham, 2006). The meanings of a child and childhood have undoubtedly changed over time. This is illustrated in the work of Aries (1996) that provoked debates about the nature of childhood. He states, controversially, that in medieval times childhood did not exist. More recently, this has been debated by Pollock (1983). She argues that even if such societies did not regard children in the same way, this did not mean that they were not regarded as children.

The ambiguous position of children persists in today's society. Children are constructed in a variety of ways. Christensen (2000a) describes the symbolic nature of the child in
Western society. The child is a symbol for the innocence that has been lost in adulthood, the child embodies the "spirit of life", the ambiguity of fragility and vitality. Children are constructed as "vulnerable" and when they are ill, they are particularly so (Christensen, 2000b in Prout (ed) 2000, p.39-59). She argues that children are positioned as dependent and passive in society in a way that denies their own understanding and perspective of their bodily experiences. Christensen undertook an ethnographic study of childhood illness among 6-13 year old Danish school children. She concludes that children were encouraged to be active and participatory in many situations such as sport and manual work projects. This was in contrast to when they were ill when she observed that there was an anticipated passive role when the child was sick or injured. She argues that this implies the position of the adult as "active, protecting and responsible" (p.39) in relation to a "passive" and "unprotected child." Importantly, this notion of the sick child runs counter to the ideals of dignity to do with autonomy, agency and respect.

Rosen (1995) provides this quote to illustrate how there are some ways in which attitudes to, and anxieties about our children have remained constant as illustrated by the quote:

"From the day your baby is born, you must teach him to do without things. Children today love luxury too much. They have execrable manners, flaunt authority, have no respect for their elders. They no longer rise when their parents or teachers enter the room. What kind of awful creatures will they be when they grow up?" (Socrates (469-399 B.C.) cited in Rosen, ed.1995, p.6).

Cunningham (2006) demonstrates how debates concerning the most appropriate way to bring children up and discipline children persist and reflect characteristics of society at the time. In 1900 the infant death rate was as high as it had been sixty years beforehand (Cunningham, 2006). In response, the wisdom of science and hygiene dictated how babies should be brought up.

Child obedience and recognition of authority was the aim as it had been in Puritan days. The influence of behavioural psychology offered routines to instill these qualities and persist today (Cunningham, 2006). Ambivalence and vacillation between protection and control persists, for example corporal punishment was abolished in schools as late as 1982 and remains allowable in the home today.
Anxieties endure about nature of childhood. The "state of youth" has become a popular subject of debate in academic, policy and media circles and publications of research into contemporary childhoods (Margo and Dixon, 2006). The 'disappearance' of childhood, as reflected in the media with headlines such as "Modern life poisoning childhood" (BBC.news [online], 2006b) have provoked large scale enquiries into junk food, advertising and testing in schools together with the impact of working mothers to the condition of today's childhood (Johnson, 2006). Control is advocated through television such as the populist programme "Supernanny", and drugs such as those to control attention deficit hyperactivity disorder (ADHD) (Coppock, 2002). The pendulum of debate continues to swing between too much homework and not enough, academic league tables and the freedom to be a child. The acknowledgement of changes in communities, family and opportunities for children signal detrimental effects on youth and the wider society (Margo and Dixon, 2006).

2.3.2 The sociology of childhood.

Since the 1980's the sociology of childhood has become established as an academic discipline and a division of sociology in its own right (Mayall, 1998). Bendelow and Williams (1998, p.137) position the child as an active agent in society and comments on the:

"sociality of children, their wish and ability to participate in constructing, maintaining and modifying the social order."

Rather than the child being seen as a primitive creature, driven on the whim of instinctual urges, in need of civilizing and thereby the target of adult socialization, the child is placed centrally and playing a key part in society. Nevertheless it is acknowledged:

"Children's lives are lived through childhoods constructed for them by adult understandings of childhood and what children are and should be" (Mayall, 1998, p.1).

Thus the child is constructed and reconstructed when ill by adults. The child is continually thought of symbolically, as described above, or relationally. James and Prout (1997, p.74) state:
“Whether in relation to education, work and employment, or in respect of their spiritual, physical and mental well-being, children are judged, nurtured and protected with the future adult in mind.”

Christensen (1998, p.44) concludes that:

“These perceptions may not necessarily attribute value to childhood and the child in their own right, as children are being judged only in relation to an adult world.”

If children are judged relationally to adults then their dignity is likely to be considered relationally.

Graue and Walsh (1998) write from a social constructionist perspective and acknowledge the importance in research of the social, the historical and the cultural in the research context, including the researcher. Context is all important. They write as Professors of Early Childhood Education and differentiate their position, in particular from the psychologists, by focusing on what goes on between rather than within their research participants. The position that I am taking is at a rather more individual level and one that looks for meanings that are, to an extent, transferable between contexts.

One of my initial questions was: “Do children acquire dignity?” and, “if so how do they do so?” And “what role do we as carers have in this process?” A collection of sociological readings compiled by Waksler (1991) explores and critiques the whole concept of the socialization of children. She argues for children as active agents rather than passive recipients in socialization.

In keeping with a social constructionist paradigm (Berger & Luckmann, 1967) I started to consider a child and childhood as objective and subjective concepts. Both as an alternative way of considering the child and childhood, but also as a device for understanding the way children are considered and dealt with in society. More precisely, it seemed an approach that could shed new light on the dignity of a child in a hospital setting. My intention in considering the child from this stance is not to disregard the biological and developing organism of the child, but as an alternative to the medical/developmental gaze.
James, Jenks and Prout (1998, p.195) describe four constructions of the child as social phenomena. In so doing they attempt to provide an "analytic framework" to consolidate an "array of childhood studies and to indicate trails and pointers for the development of future work." Their four constructions are: the social structural child, the socially constructed child, the minority group child and the tribal child. The social structural child sees the child as located on the generational continuum. The socially constructed child emphasises the cultural relativism in constructing the child. The minority child is positioned in relation to rights and citizenship, and the tribal child is constructed by identifying their lives and culture as anthropological phenomena.

When it comes to being ill, children are acted upon by adults around them through what Frankenberg (1990, p.356) terms the somatic aspect of the body. This is the objectification of the body beyond its subjective experience. According to Christensen, 1998, p.45), adults validate "objective realities" of an illness or injury and localize it within the "culturally dominant categorization of the body and its parts" rather than the subjective experience of the child. Thus if you ask a child, of a certain age, where they are hurt they are likely to answer: 'on the table' or 'in the playground' rather than telling you where on their bodies they are injured.

Children are seen to need nurturing and protection. Caring for a child is construed as natural and does not need to be reciprocated. The end result of care may well be positive - they get better and grow up into adulthood. If they die, they are doubly special as they are denied their natural right to grow up into adulthood. It is interesting to note that children’s hospices are among the most successful fund-raisers in the U.K. (Lawton, 2000 p.199). However, the care of some children is considered a burden, that is the child with a disability. There is a growing literature concerning the cultural meanings of disability (2.2.6). Some of this literature recasts many of the difficulties faced by the individual with a disability, as a failure of society in meeting their needs through social organization (Shakespeare and Watson, 1998).

If constructions of childhood have changed over time in accordance with the changing society, one aspect that has not altered is the legitimated power and control adults use over children. Originally this authority was derived from religious discourse and ideology,
However, in the late nineteenth century the child has fallen under the gaze of professionals and in particular has become constructed and interpreted within the scientific discourse (Coppock, 2002).

The inequality of power and the perceived vulnerability of a child is summed up by Christensen when she states:

"Paradoxically, while we are moved by the image of a sorrowful child, we also welcome it, for it can arouse pleasurable emotions of tenderness, which in themselves confirm adult power" (Christensen, 2000b, p.42).

The restrictions of rights to children are arguably a reflection of their position as relational or incomplete persons. Priestley (2003, p.62) notes a parallel between disabled people and children:

"Both have been denied attributions of agency, competence and civil rights. Both have been subject to differential mechanisms of surveillance and control by more powerful, non-disabled adults through policy and institutions."

Educationalists contributed to the earlier sociological approach to the child and childhood, particularly from the U.S (Graue & Walsh, 1998). In the last ten years, there has been a huge upsurge of interest into the sociology of childhood in the U.K. The 'new sociology of childhood' (James and Prout, 1997) takes a standpoint that identifies children as social actors in their own right, participating in and interacting with their environment as any adult. It is a position that has developed in response to four main drivers:

- a critique of the more traditional approach to developmental psychology,
- the promotion of children's rights as a progression to feminist ideology and research.
- an embracing of qualitative research methods as a way of exploring the context and subjective meaning of the worlds of children.
- the development of participatory research as a way of involving participants.
Despite the contribution of developmental psychology through observational studies, Graue and Walsh (1998) are critical of some of the early traditional methods in developmental psychology and medicine that have focused on measurement. They argue that in the pursuit of "technical elegance", the theoretical link between the topic of interest and its measured representation is lost. They give the example of researchers counting the number of times children poke each other as a measure of aggression. However, as they point out, the situation is more complex, commenting that, if asked, the children describe those they are in physical contact with, and poke, as their friends.

Developmental psychology has, in the past, described children as developing beings, focusing on the way children learn to become adults and full people. It is an approach that strives to define generalizable laws of development. Priestley (2003) describes this as the "tyranny of 'normal child' development". An array of standards have been developed and children measured and compared in terms of their:

"growth and morphology, locomotion and physical coordination, speech and language, sensory perception, cognition and reasoning, intelligence, reading age and so on".

For those who fall short or outside of the norms, judgments are made and interventions determined.

Research that has been designed to investigate children in the laboratory, or only in environments such as classrooms, is buffered from history and culture. This underplays diversity and the experience of the individual child in his or her culture and context. Recently, such work has been criticised from within psychology, for attempting to describe universal truths about children and ignoring gender, class issues and contexts (Smith and Cowie, 1991). Hogan (2005, p.36) suggests that divisions between developmental psychology and sociology are unhelpful and notes the "emergence of alternative models gounded in constructivist paradigms", allowing psychologists to "pay more attention to the ways in which children experience their lives."

Alderson (2000a) argues that older beliefs about the ignorance and inexperience, unawareness, unrealistic and self-centred thinking have influenced professional and
public thinking about children and childhood. Protection and control without the need to consult children has become the norm. Such beliefs have influenced research studies undertaken with the view that children are in the process of becoming rather than beings in their own right (Balen, et al, 2006).

The new sociology of childhood challenges the attitudes and accepted practices of adult society, which tend to see children as incompetent and irrational. Instead, it acknowledges the abilities and knowledge of children. Sharp divisions between child and adult are challenged. Alderson (2000a, p. 242) in her discussion of the participation of children in research, calls for an “equal respect for the worth and dignity and rights of all human beings.”

2.3.3 Children and the political climate

The notion of the child and childhood is described here at a point in time from a particular perspective that is historically, culturally and personally bound. Mayall (1998) makes the point that feminism has challenged the way sociology has developed from the perspective of men until the 1960s, while children have been invisible to the sociological gaze. Nevertheless, in the last fifteen years there has been a growing interest in children and their rights that has followed directly from the women’s movement. This has been influential in raising children and childhood further up the political agenda, both internationally and nationally. Factors that influenced the context of research were the greater acceptance of the family as important in the well-being of the child and the associated adoption of family centred care and increased presence of parents on the ward. A review of a number of key documents illustrate this transition and the greater visibility of children on the socio-political map relevant to the care of children in hospital:

- In health care the influential Report of the Platt Committee (1959) brought to the attention of society the welfare of children in hospital.

- The United Nations Convention (1989) on the Rights of the Child (UNCRC) (Unicef, 2007) was ratified universally, with the exception of Somalia and the USA. The Convention asserts human rights for all children including rights to survival, development, protection and social participation (Priestley, 1998). Alderson (1994) makes the point that the human rights agenda was conceived
originally with a view of personhood and citizenship that was based upon attributes such as autonomy, rationality and freedom, not qualities recognized as belonging to children.

- Also in 1989 the *Children Act* provided a framework for the care and protection of children. Franklin (2002, p.4) critiques the Act as one which "carefully straddles the divide between protectionist and participatory rights" and allows for a falling back upon paternalistic assumptions of children's incompetence.

- In 1993 the Audit Commission identified and audited six quality standards for caring for children in hospital across the NHS. These were: children and family-centred care, staff with specialist skills, separate facilities, effective treatments, appropriate hospitalization and strategic commissioning. The report reiterated the need for constant care and support from parents and family centred care.

- Advice regarding the implementation of the UNCRC into the National Health Service was set out in a *Practitioner’s Guide Child Health Rights* (British Association for Community Child Health, 1995).

- The *National Service Framework for children and Young people* (Department of Health, 2003; 2004a; 2004b; 2004c; 2004d) was an attempt to outline standards for health care provision for children and young people. At the core of the policy is an explicit commitment to the planning and delivery of services with the child and the family at the centre of the process.

- Policy documents such as *Every Child Matters* (Department of Education and Skills, 2004) set out principles for the well being of children from birth to nineteen in the UK. The commitment to multi agency working and the establishment of a Children's Commissioner demonstrate the rise of children on the political agenda.

The notion of family centred care has evolved in contrast to the barring of parents from children's wards in the 1940's. This followed recognition of the family as key to the care of their children. Influential to this shift was the film by James Robertson (1953) *Johnny Goes to Hospital*. This controversial film showed the distress of a child separated from
his mother, identified as maternal deprivation (Cunningham, 2006). The NSF (2003) purports to "lead a cultural shift, resulting in services being designed and delivered around the needs of children and families." Although there is a widespread acceptance of the ethos of family centred care, there is evidence to suggest that the principles of family centred care are not always executed in practice (Petersen, et al, 2004).

An interesting perspective on the rights of children in hospital comes from Shields et al (2003) who asks who owns the child in hospital? She raises the issues of best interests and how a discussion of ownership can influence the interactions between parents and health professionals. A contemporary case study, described in the media, concerning issues of ownership and rights to life, concerns Charlotte Wyatt and her family (BBC News [online], 2004). Aged one, Charlotte was deemed by the health professionals looking after her to have such a poor quality of life that they did not think it appropriate to resuscitate her if the need arose. Further "aggressive" treatment was not in the interests of the child. Her parents disagreed and despite a court ruling to say that the doctors should not resuscitate, Charlotte survived to be discharged from hospital, albeit with supportive care. By this time the parents had split up, reportedly subsequent to the strain of the preceding years and were not in the position to provide a suitable home for Charlotte (Yeoman, 2006). A foster home has been sought. Her case reflects the position of the child within society and law and the flawed concept of best interest. Taylor (1999) states that in law the state owns the body to be treated, and the body is merely tenanted by the child and managed by the parent.

2.3.4 Experiences of children and their families in hospital.

As part of my literature review I explored studies that had looked at the experiences of children and their families in hospital, particularly those using qualitative participatory methodology. This was in the absence of any empirical studies looking at dignity and children being available to review. My review of this literature included mothers' experiences of their child's recovery in hospital and at home (Darbyshire, 2003), the experiences of children on mechanical ventilation, (Noyes, 2000) the experiences of families with a child who are 'failing to thrive' (Thomlinson, 2002), the experience of being a parent of a technology dependent child (Kirk, et al, 2005). I also reviewed some
quantitative studies such as Piira et al (2005) who undertook a large scale study investigating the outcomes of parental presence at medical procedures.

Noyes (2000) took a phenomenological methodology to explore the experiences of children who require mechanical ventilation and their parents. The respondents expressed their concern at not being able to take part in activities and their lack of autonomy and control, they felt talked down to and experienced a childhood that was out of the ordinary and where they were bombarded with stimuli that were often unpleasant, yet deprived of normal contact with parents. Noyes reflects on the way the children were under constant surveillance yet could not always communicate their distress. She concludes “They experienced inequity, and their basic human needs for attachment, security, communication, friendship, continuity and belonging were not met” (p.779). Although Noyes is not investigating dignity per se, some of her findings are relevant to the experiences of worth and personhood these children reported. The extreme sensory deprivation she describes bears an uncomfortable resonance with descriptions by Levi (1995; 2.2.8).

An interesting paper by Gasquoine (2005) describes the lived experience of mothering a child in hospital during an acute illness or following injury. She takes a phenomenological approach to her study and discusses the importance and meaning of “the little things” that are done by the nurses for the children and their families and what significance they have to the mothers.

Craig and Scambler (2005) also looked at the experience of mothering, this time with disabled children and gastrostomy feeding. They used qualitative interviews with mothers attending a paediatric tertiary referral centre. Of relevance to dignity were their resultant discussions concerning nurturing and the inevitable coercion associated with feeding. Craig and Scambler also discuss the sense of stigma experienced by some of the mothers from both the means by which they needed to get sustenance into their child and by the visability of a invasive tubes and thin appearance of their child which attracted unwanted public attention.

Kirk et al (2005) also look at how parenting is constructed. They argue that no model of parenting exists for parents of a disabled child. “They have to come to terms with not
only the loss of a ‘normal child’ and family life, but also with their expectations of ‘normal’ parenthood” (p.458). They go on to suggest that their parenting far from being private, is transformed into a public activity “conducted under the gaze of healthcare workers.”

Nova et al (2005) undertook a qualitative study looking at the child’s contribution to physician-patient-parent communication. They found that the children were active in discussions contributing with their subjective experience, their own learning process of “interiorising a particular way of relating to the doctor” and their medical knowledge. However, the child’s contribution was not always integrated by the doctor and suggest that the consultation could be seen as having the potential to promote the child’s cognitive and affective growth.

The subjective experiences of children and their experience of illness has been explored infrequently, rather their experiences have been explained from the perspective of adults. No studies related to children and dignity in hospital, but those that reported their experiences raised issues that were pertinent to my study on dignity. For example Carnevale (1997) describes the experiences of seventeen critically ill children in a phenomenological study. In his conclusion he argues the “aggressive care” that characterizes critical illness and its management, overwhelms the capacity of the child to rally and regain control. Instead they adopt a stance of “near-total submission”. He continues (p.51):

“The child is sedated; tied down; deprived of every pleasure; repeatedly handled. The child is unable to vocalize: ordinary cycles (such as day/night, hunger/satiation) are flattened; noise and daylight is constant. The child’s body is continually pierced. Potent drugs perpetually alter the child’s physiology.”

He argues that the child is thus unmade and has to be reconstituted and the self remade. This period characterized by extreme distress for the child was made easier by the particular and intense attention and intensely affirming relationship with a parent or nurse. In conclusion, Carnevale calls for “loving intimates “ to be actively involved in the child’s care and that “getting to know” the child was recognized as fundamental to critical care.
Forsner et al (2005b) used the narratives of 11-18 year olds to explore their experiences of “being ill”, and of 7-10 year olds in an earlier study (2005a). The 11-18 year olds “experienced a loss of dignity when staff helped them with personal hygiene. It hurt to have no privacy in the toilet or in the shower.” Their feelings of discomfort re-awoke in the children a need to be comforted. They concluded that the experience of a short term illness was disruptive to the normal lives of the children for which they had little time to adjust. They did not know what to expect and their bodies could no longer be taken for granted. They felt hurt when they were not listened to nor treated with respect by staff. They also wanted “peace and quiet” (p.321).

Elliot and Watson (1996) interviewed children between the ages of four and sixteen at their schools about their views on health and health care in the area of Salford and Trafford. Themes that emerged included the children’s dislike of being physically manipulated by doctors and a lack of communication with doctors talking to parents in preference to them. They felt that they were talked down to. Negative perceptions of hospitals included strangeness, enormity and anonymity and they preferred home treatment where possible where they did not have to worry about privacy and confidentiality.

Smith and Gallery (2005) interviewed nine children aged between seven and eleven using write and draw techniques (see also Bradding & Horstman, 1999). They wanted to explore the preoperative information needs of children. They found that children had very varied understandings about hospitalization, but were able to express their current knowledge and enable them to raise questions about a forthcoming admission. They state that parents should not be assumed to be able to provide the necessary information for their child.

Hall (2003) in her paper on trauma and containment in children’s cancer treatment takes a psychoanalytic approach to her series of observational studies. She differentiates between external that included invasive procedures and internal trauma resulting from the child’s own body in response to the chemotherapy.

She concludes that intrusive acts are not merely physical, but have an “emotional quality” to them as well. She notes her own distress at witnessing the nursing staff make
little attempt to communicate with the child during painful procedures. During internal trauma the child is required to trust the staff with their life.

Hall records her surprise at the way a child ravaged by her own body could momentarily switch and take pleasure from, in this case the softness of some tissues. Hall goes on to discuss the defences used by the staff in their dealings with the children and noted her own avoidance of certain procedures and would “shun documenting observations” (p.117).

She comments of the role of parents in hospital with their children “When their parents are present and compliant with painful treatment, at a basic level the child must feel they have failed to protect them”. She also speculates that complaining must be difficult for parents as they risk becoming unpopular with the very individuals that care for their child.

Shin and White-Traut (2005) studied and recorded with video tape nurse-child interactions on an inpatient paediatric unit in Korea. They used Bales Interaction Process Analysis (1970) to analyse the triadic interaction between nurse, child and parent. They found children to be passive participants with the nurses interacting with caregivers (usually mothers), in preference to the child.

Wawszczyk (2005) provides a rare personal account recording her own experiences of cancer as a teenager. She recalls how difficult it was as a fourteen year old on a children’s ward:

“You are acutely aware of your body, it is very upsetting to be totally reliant on your parents and nurses for even the most basic washing, toileting and feeding – and without much privacy” (p. 370).

She also talks about her experience of being isolated and “unclean” due to MRSA in her Hickman line. She craved for normality and battled to get used to a complete loss of privacy and powerlessness with “every part of my body under scrutiny” (p.370). She concludes by commending her consultant who saw her as a human being, as “Ruth”, rather than a “cancer patient”.
2.3.5  Researching children

As a reflection of the change in the construction of children in society, ways of undertaking research with children, instead of on children have developed alongside the evolution of the child and children in society. The trend has been for methods to be increasingly participative in an attempt to hear the voices of the children, as evidenced by the literature. The new sociology of childhood described above is less about grand theories and more about describing the richness of the lives of children in different contexts. Akin to this is a commitment to qualitative research methodologies. This was, in part, a reaction to positivist approaches to research and to quantitative methods.

In contrast to the laboratory research of developmental psychologists in the 1950s and 1960s, context when researching children is very important. Graue and Walsh (1998) define context as “a culturally and historically situated place and time, a specific here and now” They go on to differentiate between a local context where the research is being conducted right here right now, such as the hospital ward, and the larger context.

An early example of participatory research with children in the context of the school is reported by Mandell (1991). In the anthropological tradition of ethnography, she chose to attempt to “go native” and immerse herself in the worlds of her subjects by adopting the role of one of her research subjects. Of course, as she acknowledges, this was not possible when researching the worlds of children. However, Mandell (1991, p42) took on what she terms the “least adult role.” She reports:

"While my size dictated that I could never physically pass for a child, I endeavoured to put aside ordinary forms of adult status and interaction - authority, verbal competency, cognitive and social mastery in order to follow their ways closely."

Participatory research methods ensure and assert that those who are the subjects of the research, the children, are involved in the process. In the same way that children are seen and acknowledged to participate in the world, they are encouraged to take part in the process of research. In every day life, children are often denied a role in making decisions about issues that will affect them.
“Adults construct children as essentially non-competent, or at least, as competent only in specific ways and within certain parameters” (Hutchby & Moran-Ellis, 1998, p.7).

Waksler (1991, p.62) warns about the biases adults have about children. She describes the way “adults set themselves up as the understanders, interpreters and translators of children’s behaviour.” The absence of explanations by children is rarely missed because it is not expected. Adults she argues, can view children as “unfinished,” “in the process” and “not anywhere yet”. As a category they are less than adults in terms of experience. Adults tend to see children as wrong or not able to understand. Yet the inability to understand, particularly concerning medical and life and death matters has been challenged (Bluebond-Langner, 1978).

Involving children in the research process is an acknowledgment of this and a positive step in enabling their voices to be heard. Alderson (2000a) makes a valid claim for children to take part in research about children. She warns adult researchers researching children that their own childhood memories, present values and prejudices about the inabilities of young children can blur the voices of children.

In determining how best to uncover the experiences of the children I was influenced by the sociology of children literature (James, Jenks and Prout, 1998; Graue and Walsh, 1998). I researched some interesting and innovative approaches (Greene and Hogan, 2005: Lewis and Lindsay, 2000: Greig and Taylor, 1999). Prior to starting the second phase of the fieldwork, I had been inspired by accounts of engaging children as active participants in the research process (Thomas and O’Kane, 1998): both in terms of becoming co-researchers (Clark, 2004) and using more age appropriate and creative tools to assist communication for example puppets and drawing (Horstmann and Bradding, 2002: Coates, 2004).

My review of the literature revealed a body of sociological works that discusses the way researchers strive to get the perspective of the child in research. Waksler (1991) suggests that adults are unable to study children. However she says that sociologists (and no doubt other researchers) are, if they are able to suspend their adult roles in the same manner as they must suspend other partisan roles when they undertake research. This of course leads me on to debate whether researchers are ever so self aware to the
point where they can separate out and suspend parts of themselves to develop an objective theory. Nevertheless, it has been the tradition of anthropologists who, using ethnography, have gone into the field to study a society and culture that is different from their own. Is there such a difference when we study children, as long as we are able to acknowledge our assumptions and textual embodiment of ourselves. We may even be freed up able to use our own lives as autobiographical texts to enlighten our data collection and analysis. I will return to these research principles in the Methodology chapter.

2.4 Summary of Chapter Two: Review of the Literature

I have presented this literature review as two distinct streams: dignity and children. My approach to reviewing the literature for both areas represents historical, theoretical and empirical perspectives. I have represented dignity as objective and the attempts to understand dignity as subjective. Likewise I have taken an objective look at the construction of the child and childhood in society and ended with accounts of the subjective, from macro to micro. I have attempted to put the literature in the context of the present day with examples from the media. In so doing I have created the backdrop for undertaking the fieldwork.

There were areas that I chose not to study in the literature. In particular I did not review literature that explored the related concepts of dignity such as self-concept, identity and self-esteem that have their roots in the developmental psychology. This was a positive attempt to avoid equating dignity with other associated concepts. I sought to explore dignity from a sociological paradigm and to view the field with a sociological, rather than the more familiar (to me as a nurse) clinical gaze.

It is apparent from a wide range of literature that authors agree that more than one type of dignity coexists. How these types are categorized, and what identifiable qualities they have, are the subject of much debate. It is evident too that some of these definitions seem not to be applicable to children. As a way of forging competing notions of dignity with competing notions of the child I have taken the four sociological dichotomies of the child as described by James, Jenks and Prout (1998), and transposed constructions of dignity from the literature (see Figure 2 overleaf).
Theoretical Field for the study of dignity and children in hospital
Adapted from Theoretical field for the social study of childhood (James, A., Jenks, C. & Prout, A. 1998)
with the meanings of dignity from the literature review overlaid in italics.

Figure 2
Of all the types of dignity referred to in the literature the notion of an intrinsic dignity inherent in all humans seems most relevant to the study of children. However this understanding of dignity is based upon the premise that all humans are of equal value, yet evidence from the sociology of children suggests that children are in many ways marginalized as if they constituted a minority group. At a political level the notion of intrinsic dignity is enshrined in the universality of rights. The vulnerability of children provoked the later Convention on the Rights of the Child (Unicef, 2007) and the ratification of human rights in the recognition of children as a social structural category, almost as a class of its own, similar to feminist ideology.

Where dignity is understood as a social, extrinsic or contingent category, children seem to lose out. If children are constructed as unfinished adults and 'becomings' rather than beings they will not be conceptualized as of equal worth. If dignity is the consequence of achieving high office or demonstrating moral stature over the course of a lifetime then children are disadvantaged by their limited years. How children are socially constructed is culturally based and particular in this research to the ward setting and this warrants investigation. The fourth discourse of childhood offered by James, Jenks and Prout (1998) is the Tribal child with a culture of their own. The agency of individuals is central to dignity and is important for the tribal child. Hospitalisation presents a challenge to agency.

It is apparent from the literature that the association between dignity and the child has not, until now, attracted much concern. The proliferation of interest in dignity and older people brings into stark relief the dearth of research into dignity and children.

In the Literature Review I have discussed the concept of dignity: conceptually and theoretically, from the applied literature and methodologically. I have also explored the nature of the child and childhood and the way children are socially constructed. In deciding the methodological approach I should best take for the study, I held what I had learned of the two concepts of dignity and child. I was conscious to adopt a methodology that did not exploit participants, that did not humiliate or degrade in any way, but upheld their dignity. After reviewing the literature I wanted to see and hear the stories of the children and those caring for them.
The literature demonstrates a new commitment to the participation of children at the levels of consultation, policy and practice across social, health and care settings. It seems timely to explore the meaning of dignity for children, their parents and staff and investigate their experiences in hospital. It is from the two key areas of inquiry, that are Dignity and Child, and their related themes, that I have developed and refined my methodology. It is to the methodology that I will now proceed.
Chapter Three

Methodology

3.1 Introduction

In this chapter I will outline the epistemological position I took for this research and how this influenced my choice of methodology, namely ethnography and grounded theory. I will discuss these two methodologies in turn and discuss how they were combined and used in this research. I have outlined the periods of fieldwork in the study diagram (figure 3) overleaf, giving an indication of how the methodology evolved as the study progressed. You will note an evolution in emphasis between the Pilot Work and the Main Study from the child to the child in context. This is reflected in the way my aims and objectives were refined for the Main Study.

I discuss the fieldwork from pilot work to the main study. I explore the challenges of gaining access to the sites and the participants at the level of the institution and the individual. I outline the role I assumed as researcher and how this evolved and reflect on some of the practical challenges I faced during the course of the fieldwork. I explore some of the ethical issues that are pertinent to my choice of methodology and, in particular, how they relate to a study focusing on the experience of children and the meaning of dignity for them, their parents and the staff on the ward. I detail how I identified and recorded data both as observations and through interview. I describe the process of analysis of the data that was a continual and iterative throughout the research. I demonstrate, with reference to appendices, how I interpreted and reconstructed the data to develop a theoretical interpretation of the meaning of dignity for the child in hospital.

Finally I discuss the meaning of reflexivity in qualitative research and its integral part in the research process. I will explore the notions of credibility and fittingness and the importance of a demonstrable audit trail in qualitative research and consider the application of traditional methods of evaluating research and their applicability to a grounded theory ethnography.
Dignity and the Child in Hospital: Study Diagram

Methodology

Literature review - ongoing
Ethical Considerations - ongoing

Pilot Work
Ethnographic study based on 2 children’s wards in NE London over 4 months
Additional pilot work in a nursery, school and children’s hospice.

Feasibility of chosen methodology
Development of initial indicators and constructs

Main study
Ethnography and grounded theory
Children’s Ward
District General Hospital
April 2005 – December 2005

Staff interviews
16 members of staff incl; medical, nursing and physiotherapy staff, student nurses and health care assistant.

Child & Parent Interviews
31 interviews

Observations
97 children and their families, staff and the environment

January 2006 – April 2007
Completion of analysis, discussion and writing up of thesis

Analysis

Strangeness
Social construction
Symbolism
Players and the environment
Witnesses, public and private
Body and control

Figure 3
3.2 Choosing a methodology

3.2.1 World view and epistemological position

In choosing my methodology I have adopted one that is appropriate to my world-view, that in turn is influenced by my autobiography. This has become more apparent to me as I have written up my thesis and I recognised how my world-view is consistent throughout. I have, in the past, been influenced by the work and principles of the psychologist and humanist Carl Rogers and the person/patient centred approach to others that underpins his philosophy. The notions of unconditional positive regard, congruence and empathy have run through my own understanding of dignity and children, through the methodology, data analysis, findings and discussion.

An associated theme that runs throughout the thesis is the interplay between science and art. My own previous life as a professional dancer has influenced my way of seeing the world and my research setting. It is not only the language of the theatre that I have used to describe my findings, but the concepts of performance and interpretation of meaning. Sandelowski (1993, p.3) describes qualitative research as a bridge between the realms of art and science. In the same way a dancer may use her body to perform technically demanding steps, so a qualitative researcher can execute the practices of listening, recording and writing. She then uses herself as a tool for hearing the subjective lived experience of another and giving her interpretation to construct her story for her audience. In the same way a dancer would give her own interpretation the music and role, so a qualitative researcher can interpret the voices of the participants to reconstruct their stories for her audience.

The tension between the objective and the subjective is a theme that permeates the research through from methodology to data analysis. As researcher I was aware of the need to objectify and operationalise the concept of dignity so that it could be more deeply understood by taking account of the subjective experiences of the child and their parents in the extremely challenging context of the children's ward. My own methodological position has shifted from the inception of the study. Initially my emphasis was on defining dignity and clarifying the meaning of dignity as a concept and academic exercise albeit with practical implications and recommendations to inform practice. Latterly my position has moved increasingly towards acknowledging the subjective and...
drawing out meanings from participants, the children, their parents and the staff, to generate theory. My investigation of dignity reflects this shift with the nurses offering a largely objective understanding of dignity and how it relates to children, through to the children who represent a subjective appreciation. This shift is evident in my rendering of my pilot work and the Main study. It is noteworthy that discussions of the meaning and promotion of dignity for the child at ward level also reflect the tension between the objective and the subjective.

3.2.2 Ethnography.

As there had been few previous empirical studies researching dignity (2.2.4), I sought a primarily inductive approach. Ethnography was appealing as it gave me the opportunity to position myself within the milieu of the hospital ward with the aspiration to gain insights into the worlds of the research participants. Instead of watching the participants as goldfish in a bowl, it allowed me to jump in there with them. In adopting an ethnographic approach, my aim was to acknowledge different subjective experiences of personal dignity, in a domain, the hospital, that traditionally values objective truths. An ethnographic approach provided me with a way of exploring the issue of dignity in the context of the hospital ward. My interest started off as a puzzlement about dignity, what it was and how it related to children as a concept, rather than a quest for the answer to a burning question(s). The iterative and evolving nature of ethnography with the way forward being determined by what has gone before, allowed me to build on my initial musings as my research progressed.

Ethnography has been used in anthropology for nearly a century and has been used to gather data about people first hand, in their natural setting, through observing and questioning (Baillie, 1995). In recent years this approach has become popular amongst researchers of other disciplines. Ethnographic approaches have been taken by social workers, educationalists and nurses undertaking research in their own field (Emond, 2005; Smith, 1992). Smith (1996) describes the modern ethnographic enterprise as one that includes the detailed study of particular groups in a range of settings, with the ethnographers focusing on the interactions taking place and their meanings. Naturalistic observation is key and is used to provide detailed studies of particular groups in a range of settings with the ethnographer focusing on the interactions taking place and their
meanings. Ethnographers may also look at how these individuals in their settings reflect the wider society. Hammersley and Atkinson (1995) state that ethnography exhibits the following characteristics:

- an emphasis on exploring the nature of particular social phenomena, rather than setting out to test hypotheses about them.
- a tendency to work primarily with unstructured data.
- the investigation of a small number of cases.
- the analysis of data that involves explicit interpretations of the meaning and function of human actions.
- quantification and statistical analysis play a subordinate role.

My approach to the Main Study was informed by previous pilot work, the report of which is included as Chapter Four. In both studies, I took an ethnographic approach adopting the role of a participant observer and immersing myself in the culture and the context of the hospital children’s ward. For both the pilot study and the main study, I collected documentary evidence, such as the mission statement of the ward and the information given out to parents and the children. This gave insights into the context and the ethos of the ward and hospital management and administration.

The hospital ward defined my sample as the children and their parents and the staff that were on the ward, as well as determining the age of the children in the study. Thus the meaning of ‘child’ and the age of a child were determined by whether they were admitted to and cared for in the children’s ward. I have used the term “child” throughout, rather than “young person” as a reflection of their status on a “children’s” rather than “young person’s” ward.

3.2.3 Grounded theory.

I applied a grounded theory (Glaser and Strauss, 1967) approach to the interpretation of data and to develop hypotheses about the nature of dignity in the child. I used grounded theory as a way of structuring my enquiry and analysis. I found that grounded theory provided a structured approach to the continual development of theory from data. By integrating grounded theory with ethnography I was able to give priority not to a description of the environment, although this was important, but rather to the process
and phenomena and from the outset make a “conceptual rendering” of the activities of the research participants (Charmaz, 2006, p.22). Rather than observing a scene through one lens, I allowed processes to come into greater focus and the environment become the backdrop.

Grounded theory was first developed by Glaser and Strauss (1967) in their study of death and dying:

“Glaser and Strauss aimed to move qualitative inquiry beyond descriptive studies into the realm of explanatory theoretical frameworks, thereby providing abstract conceptual understandings of the studied phenomenon” (Charmaz, 2006, p.6).

Despite an evolution of grounded theory, the principles remain constant. Later theorists have emphasised the constructivist nature of the process, for example:

“Grounded theory methods move ethnographic research towards theoretical development by raising description to abstract categories and theoretical interpretation” (Charmaz, 2006, p. 23).

Grounded theory is a methodology in its own right that nevertheless can be used in conjunction with other methodologies such as ethnography (Smith, 1992; Charmaz & Mitchell, 2001). Grounded theory is an approach to research and generation of theory that is primarily inductive, that is it begins with a variety of individual cases and draws out patterns that are then used to formulate conceptual theory. Charmaz (2006) explains how the researchers guiding interests, or “sensitizing concepts” (Blumer, 1969), can be used to further ideas. In this study my research interest was dignity and the child in hospital and an example of a sensitizing concept would be the role of the body in notions of dignity. I used the concept of the body whilst making my observations, asking questions and interrogating the data to enrich the data and advance analysis.

There has been made a distinction between research methods as verification or discovery methods (Gheradi and Turner 1987). The latter they describe as “messy” and one in which order is not immediately attained, and as “intriguing” where conclusions are not known prior to the investigation being carried out. Discovery methods include grounded theory that, as its name infers, is a ground up approach to investigation and
theory generation. Nevertheless, verification is inherent with in the grounded theory approach as it evolves through constant comparison of data.

Grounded theory, particularly from a Glaserian approach, does not seek to find answers to research questions rather it begins with a "general wonderment" (Cutliffe, 2005) about a topic and from collecting data it is a way of developing theory from the outset. Data are systematically structured through coding then worked and reworked through levels of abstraction. Grounded theory emphasises the participant's own accounts of social and psychological events and of their associated local phenomenal and social worlds, in other words their subjective understandings. It is an approach appropriate to apply to a study of a subject area, such as dignity, where previous research is sparse and the knowledge base undeveloped (Field and Morse, 1985).

3.3 Fieldwork
3.3.1 Access to Fieldwork

I undertook the fieldwork in three distinct phases with the major portion undertaken from January 2005 – December 2005. Prior to fieldwork commencing, I had to negotiate access.

3.3.1.1 Access to the pilot site.

The initial exploratory pilot study took place at a large district general hospital, serving a diverse population in North-East London. I was based on two children's wards, over a two-month period, in 1999.

Prior to undertaking any research I needed to ensure that all the necessary consents had been obtained. I sought ethical approval from the Local Regional Ethics Committee. In preparation for Local Research Ethics approval, I have found the Guidelines for the ethical conduct of medical research involving children (British Paediatric Association, 1992) particularly useful. More recently I have used Medical research involving children (Medical Research Council, 2004).
The role of the Ethics Committee is to ensure that the aim of research is sufficiently valid and ethically acceptable and provide a system for the proper scrutiny of medical research. They pay special attention to research proposals involving groups deemed as more vulnerable including children, particularly in relation to consent (Tierney, 1995). "An examination of the ethical acceptability is necessary to protect the dignity, rights, safety and well-being of the research participant" (MRC, 2004). Such committees run the risk of being classed as overprotective and paternalistic and marginalising of the voices of children in their attempts to protect the potentially vulnerable.

I was required to present my proposal to the Ethics Committee in person before granting approval as they had doubts about the qualitative nature of the proposal and lack of concrete questionnaires to use with the children.

Baillie (1995) highlights the difficulty of gaining approval for qualitative studies where the rigour of the study may be judged on quantitative criteria such as objectivity. However, qualitative research is becoming more widespread in medical/nursing research. It acknowledged to be key in developing concepts that help us understand social phenomena, where they emphasise the meanings, experiences and views of the participants in a natural rather than experimental setting (Pope and Mays, 1995).

Permission to undertake the study was also granted by the Manager of Children's Services and I made links with the Nurse lecturers in Child Health at the associated university. The main aim of the pilot was to establish the feasibility of studying dignity taking an ethnographic approach and to identify any practical difficulties.

3.3.1.2 Access to the Main Study

The main ethnographic study was carried out at a District General Hospital, on the Children's Ward from January 2005 – December 2005, with the fieldwork concentrated in the period between April and December. The sample was defined by the ward population and included children from birth to sixteen.

Ethical approval was sought and granted through the South West Surrey Local Regional Ethics Committee and through the Ethics Committee of the university (Appendices 4 and 5). Again the structure of the application form lent itself more readily to quantitative
methodologies. For example Question 3 of the application form asked for "the hypothesis which it is intended to test". This meant that it was difficult to describe the nature of the research as it did not fit neatly into the criteria specified.

Access to the ward was negotiated with a Consultant Paediatrician who was the Lead Clinician for Paediatrics, the Matron who oversaw the provision of services for children in the hospital and the Ward Manager, who was a senior sister responsible for the running of the children's ward and the care of the children on the ward. On a daily basis, access was agreed through the nurse in charge and finally the family and children themselves. Rachel (1996) notes that access is granted at a number of different levels. Access needed to be negotiated and renegotiated throughout the research and even once on the ward, I was excluded from areas, individual children and information. I had to negotiate and renegotiate on a day by day, hour by hour, minute by minute basis what I was and was not allowed. I shall return to this in the Findings chapters.

It was a condition of the ethical approval that I was not allowed access to the medical notes without modification to the information sheet (Appendix 1) and consent forms (Appendix 2) and the further approval of the Ethics Committee. When I spoke informally to the consultant and ward manager they made it clear that they would oppose this request. This did create difficulties that I discuss more fully in the Findings chapters.

3.3.1.3 Access denied – the children's hospice.

As a contrasting perspective and construction of the child and their family I wanted to spend some time at the local hospice caring for life-limited children and their families. Having also had a close friend with a child who had been cared for at the hospice I knew something of what it meant to have a life limited child. I was interested in the way the lives of life limited children and their families were cared for both in respite and at the end of life. Having spent several months on an acute ward I was curious to hear the experiences of those who were cared for in a way focusing on the day to day quality of life rather than quantity, the experience of the present rather than with the future of the child in mind. I wanted to represent the voices of these children and their families concerning what dignity meant for them.
Despite letters, a meeting and submission of a refined protocol (Appendix 6), access was denied. It was thought that any research would be disruptive to the lives of the children and their families at a time when they had sought refuge at the hospice. However I was invited to spend a morning with a senior staff member so that I could explore more fully the ethos of the hospice.

3.3.2 Researcher role

The purpose of my research was to investigate the meaning of dignity for the staff and the way it is performed and the meaning of dignity for the parent and child in hospital. Fundamental to the success of research is the researcher and the appropriateness of the role they adopt during the process. My past experience as a nurse was helpful in many ways. For example I had an affinity and understanding of nurse roles and the hospital culture. During the Pilot Study I found it was easier to identify with the nurses, as I had been one for several years, rather than directly with the children. In the Main Study, I found myself feeling an allegiance with the parents as I had become, by this time, a mother of three children.

I suspect access was easier as a nurse although I sensed a suspicion that an Adult trained nurse should be undertaking research on a children's ward. The ward chosen for the main study was, at the time, experiencing considerable change and had recently re-opened after a major refurbishment of the Children's Unit. The nursing staff were concerned that I should not interfere or place any additional demands on staff, and no doubt patients, by undertaking the research.

In choosing my role as researcher I had to consider the stance that would be most appropriate in eliciting the perspectives of the participants. In much the same way as gaining access to the ward I had to gain access to individual children and their families. Peace (1993, p. 30) comments "Who you are and what you represent are crucial in gaining access to research settings" and I took some time deciding on what uniform, if any, I should wear during fieldwork. For the pilot study I wore a tabard that associated me with the Play Staff on the ward. For the main study I wore an ID card, but no other uniform that identified me in a particular role. However by not wearing a uniform I...
positioned myself obviously not as a nurse, therapist, play specialist, or ancillary staff member as they were all uniformed.

There are ethical considerations to be taken into account concerning the covertness of one's role as researcher. It is easy on a busy ward for patients and their families to misunderstand why you are there, especially when they may be in need of information or assistance. Darbyshire (1992) in his study of parents resident with their children in hospital, made his role as researcher explicit to staff and patients at the outset of his research. This upfront approach offers a direct way of approaching patients and their families when asking questions. This is an honest approach and one that I adopted. In the Pilot study, I was explicit about my role as a researcher to the children, parents and staff alike, but I was arguably still in a position of authority. It is a fine balance as researcher to be close enough to the child, but remain congruent as an adult, without being threatening in any way.

In studying the concept of dignity it seems only right to adopt a methodology that emphasises an egalitarian stance of the researcher to the researched. It is paramount that by being researched, no indignity should result. This should be the case for not only the participants, but also the researcher and ultimately the reader of the research. Participants must be respected throughout the process. When listening to and analysing data, Benner (1994, p101) states:

"The ethical stance of the interpretive researcher is one of respect for the voice and experience described in the text."

The role of the nurses, researcher and adult are all potentially powerful, especially when contrasted to child patients and their families. A relationship approaching an equal one needed to be carefully negotiated.

3.3.3 Participant observation

The participant observer role is key to the need to be part of yet distant. Participant observation is often described as the “hallmark of ethnography” (Ely,1991, p.42). Toren (1996, p.103) describes the business of the participant observer as “at once a participant
and a questioning observer of your own and others’ participation in ordinary events. My
rendition of the participant observer role varied in the Main Study from the Pilot Work,
this was the result of a degree of experimentation with the level of involvement I should
take as researcher.

3.3.3.1 Additional pilot work

In the summer of 2002, I undertook preliminary observational work at a Day Care
Nursery with 3-4 years olds and in a Primary School with a class of Year Ones (aged 5 –
6 years). This was both to collect additional data from comparable “institutions” where
children spend a good deal of their time, as well as to vary my levels of participation as
an observer.

I chose to vary my level of participation in preparation for the main study as I wanted to
see what sort of data I was able to collect whilst in these different roles. From these
different worlds that children inhabit, I wanted to see how the children reacted to me a
stranger. At the Nursery School I was a non-participant observer, or intended to be, but
the curiosity of the children meant that to be non-participative was impossible to maintain
and seemed false. At the Primary School, I was a participant observer and interacted
with the children as an adult coming in to ‘help’ under the direction of the teacher. In the
hospital setting, I talked with children and their parents and played a more active part on
the ward. I have represented my level of participation diagrammatically below (Figure 4).

<table>
<thead>
<tr>
<th>Non-participant Observer</th>
<th>Observer participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursery</td>
<td>Primary school</td>
</tr>
</tbody>
</table>

*Figure 4: My level of participation as researcher*

The experience of the pilot work led me to uncover ethical issues for me, and my
position as observer participant. For example, during the pilot study I became aware of
the potential for me to create, or exacerbate indignity just by my presence, for example
during the bathing of an eleven-year old boy with severely infected eczema. I discuss the
affect of a witness on the dignity of the other in the Findings section. I also found that as
a nurse, but not employed as such, it was difficult to "stand by" when the ward was busy,
such as when one of the sisters had to quickly draw up intravenous drugs, while I looked
on, or when I became party to confidential information about families or staff. Many
researchers, who like me, are themselves nurses, have adopted a participant observer
role (Smith, 1992: Savage, 1995.). This gave them privileged access to the goings on in
the ward. However, this can create both practical and ethical difficulties with the
responsibilities of caring conflicting with the need to collect data. I recorded (1.05.99)
how three babies were alone on the ward, without a parent. "I found myself going from
room to room trying to comfort them" (4.2.9). Whether officially employed as a nurse or
not, I found I could still experience the feeling of a dual role.

3.3.3.2 Participant observation in the Main Study

For the Main Study I adopted an observer participant role as shown in figure 4 above. I
wore my own clothes with no tabard to distinguish me from the nursing staff.
Observations of the environment, the key players: the children, their families, the nurses,
play leaders and doctors were vital data. Savage (1995) notes the importance of using
all the senses in attempting to understand what is going on. I was conscious of trying to
sensitise myself to the environment I was in and record my own responses be they
sensual, physical, cognitive or emotional. For example I recorded soon after starting the
fieldwork of the main study, my sensory responses to the ward, that I interpreted as
being shared by the waiting parents:

One part of them (like me) constantly tuned in to signals about the ward –
the smell of lunch, the clatter of the trolleys, the talking of the doctors' rounds
(14.04.05) physical, cognitive or emotional.

My emotional responses fluctuated from day to day:

Hooray, I have finished for one day. The ward feels quite 'up' or 'high' and
happy (14.04.05).

And on another day:
She fills with tears and I feel myself welling up. I wonder whether I should touch her (8.06.05).

From the period between April and September 2005, I deliberately focused upon the experiences of the children and their parents. As a way of aligning myself to the children and their parents, I limited my use of space to the areas that were available to them, therefore I did not go into either of the staff offices or behind the desk area on the ward behind which the staff would congregate. I made a note of the signage and information that was available as a child or parent and, as I was 'new' to the ward tried to orientate myself to the ward in a way that children and their parents might do. I looked at sleeping and personal hygiene arrangements, meals, interactions with staff and others. I listened to what children and their parents had to say. I also listened to myself as I identified with the mothers in particular and recorded this all as data. I experienced a sense of resonance with the different roles of nurse, mother and child. These different selves are intrinsic to my own autobiography: as a child, a nurse and a parent and this put me in an interesting and valid position. However, a greater degree of self-reflexivity is required if one is to study the familiar to protect against assumptions. I have reflected further in Chapter Three: Methodology (3.6.1) with regard to the issues of identification and self-disclosure.

From September 2005, I started to interview the staff and concentrate more upon their experiences. As a consequence, I went into the staff areas and spoke to the staff in an informal way. I offered to help with bed making, that I found I actually enjoyed. I noted my pleasure at doing something rather than seeming to do very little which in turn led me to speculate on the nurses' apparent need to keep busy. I will return to "busyness" in Chapter Six (6.3.3.1).

3.3.4 Ethical considerations

In past times, the children used as research subjects were exploited and objectified. During the first part of the twentieth century, children were used for social and medical research, without any notion of gaining their consent. Barr (1992) uses the term "spare children" in this context to include: foundlings, paupers, illegitimates, waifs and orphans, whose use no-one objected to.
Nowadays general ethical principles of research are applied to research with children. These are outlined by Beauchamp and Childress (1994) as: respect for autonomy, nonmaleficence, beneficence and justice. Autonomy means that participants are free to make a choice about participating without any coercion. Nonmaleficence and beneficence mean the good of the research outweighs any risks for the individual and society. Justice implies that the strategies used in the research are fair and just.

There are ethical considerations particular to qualitative research. Holloway and Wheeler (1995) comment on the vulnerability of patients. This is supported by Mander (1988), who claims that patients are a “captive population.” The particular vulnerability of children has been acknowledged (DoH, 1991). The parents of sick children are also open to exploitation at a time when they are particularly vulnerable and would do anything for the best interests of their child and to children (7.5.2). In recent years there has been a growth in the development of guidelines and concern to undertake research with children in an ethical way. Tensions exist in the debate concerning the child’s ability to consent and participation in research (Balen, et al. 2006, p.33).

However, the ethical debate that surrounds the potential risk to children in research, centers, in the main, on children taking part in clinical trials. Guidelines too reflect this (British Paediatric Association, 1992; Medical Research Council, 2004). Morrow and Richards (1996) dispute the relevance such guidance has to those of us undertaking research of a social nature where the risks and benefits may be less clear cut. They argue that recent sociological research that sees participation in the research process as the key to empower children by making their voices heard. However, there remains less understanding of how children view research and what influences their decisions about taking part. The participation of children in research is complex.

3.3.4.1 Informed consent

No less contentious is the ability of children to give informed consent. As described, the data collection and analysis ran concurrently and the direction of the grounded theory was driven by this process. This created a dilemma in obtaining informed consent as participants are asked to participate in research that has no precise pathway. Therefore
informed participation had to be viewed as an ongoing process. The children and parents to be studied were informed of the observational study in advance and an Information Sheet (Appendix 1) supplied. During the Pilot Study, I introduced myself to parents and children at the earliest possible moment. This was very difficult, not least because the children (and parents) were often admitted in a vulnerable and or emotional state. It was difficult to explain why I was there and that despite wearing a tabard (in the Pilot study) I was not there to be a nurse. For the main study, I chose not to wear a tabard and verbal consent was sought from the child, where possible, and their parents prior to being included in the observation. I always reported to the nurse in charge when I arrived on the ward to let them know that I was about and consent was sought in the presence of a trained member of staff. In this study I asked children, younger than school age, in their parent’s presence, if it would be all right for me to sit, watch and write my observations down. At a later time, I asked them if it was all right to ask them some questions or talk to them and record what they said on my voice recorder.

I was aware, through my observations of nurses and doctors talking to parents and children, that parents were very willing to consent to a “chat” with the doctor. Invariably, however, when they were asked ‘is it alright to have a chat here?’ the parents and child were in the dark as to what issues were likely to be discussed and could find themselves discussing issues that were rather more private than they had expected. I endeavoured to avoid any such misconceptions by devising different consent forms and revisiting their agreement to participate during the interview or observation.

I developed four different consent forms for the various participants whom I wished to interview, including two versions of the child’s consent form, one for a younger child and one for an older child (Appendix 2). At each stage child participants and their parents/carers were asked if they wished to withdraw from further study. This strategy is known as “process consenting” (Munhall, 1988). For example, I was interviewing the parents of a fifteen month old girl, for which they gave permission and then I asked for them to consent to my continued presence when their child underwent venepuncture. This was because a venepuncture, in my protocol, was defined as focused observation and as such required consent. I asked the child for their consent where they were able, in addition to the parent. Children are usually regarded competent to consent at school age (British Paediatric Association, 1992). However, the notion of competence is
problematic and I would ask younger children if it was alright for me to ask them some questions and record their answers out of regard for the child. In this study I sought parental consent after having sought assent from the child. By assent I mean an agreement by the child to take part in the research even though he or she may not understand fully its purpose. One child, aged three, did refuse despite her mother having agreed on her behalf. She turned her back on me and so I did not proceed. Her mother was apologetic, but I was pleased that the child had felt able to refuse. Competence is very hard to define, to assess and to demonstrate. Children develop at different rates and the same child may need support in some areas yet be confident in other areas. Bluebond-Langner (1978) undertook research with children aged three to nine years, who had leukaemia. She found that seriously ill young children can have a profound and mature understanding and can cope with and discuss complex and painful knowledge. In agreement with this, Alderson (2000b) concludes that when determining the level of understanding a child may have, more salient than age is his, or her, experience. Talking and age appropriate information can provide children with the means to make informed decisions about their participation and empower them through research.

The principle of 'Gillick competence' arose from a House of Lords ruling enabling a person under 16 to give consent to a medical procedure without parental consent if he or she was deemed to be 'of sufficient age and understanding' and thus make an informed choice. However, this ruling does not apply where an intervention is not therapeutic such as in the case of research. As a practical attempt to safeguard children taking part in research studies the Medical Research Council has set out guidelines concerning competence and informed consent (MRC, 2004; 5.1).

3.3.4.2 The voice of the child.

A challenge I faced throughout the study was how could I truly hear and represent the voice of the child? My initial choice of methodology was important. An ethnographic approach to the study of childhood and children is widely recognised as a useful methodological approach, especially where the intention is to explore the subjective meaning of dignity in the child. The essence of ethnography is the emic perspective (Fetterman, 1989), that is the insider's, or in this case the child's perspective. Ethnography promotes the participation of children in the research process and gives
them a “direct voice” (Franklin, 2002, p.3). This is important when trying to appreciate the perspective of the child and, as in this case, to establish how dignity is expressed and experienced by children. In adopting an ethnographic approach I sought to gather and interpret the children’s subjective experiences of their hospital stay and their impact on their personal dignity.

My earlier pilot work had suggested structured play and education to be a way to widen my interactions with the children. As in the Pilot Study, I chose to adopt a participant observer role. Once on the ward, I was surprised at the very fast turnover of patients and their families, the way that the children rarely moved from their beds, except sometimes to the playroom, and the ever-present parent/adult carer. This was also the case when during this period I also visited the Accident and Emergency department, the Playgroup and Out Patients. This meant that the potential for time alone with the children was very limited as was any place to talk or play. There was one Play Specialist on the ward and one teacher. Activities were usually undertaken on a one to one level.

The question whether adult researchers can really enter into the child’s world is hotly debated. Indeed could I really call myself a participant observer, when I was so obviously not “one of them” and not participating as such, but rather as another adult on the ward. I have an adult’s eye view. Kleinmann and Copp (1993) argue that we cannot get close to participants in research if we are not their equals or subordinates. The inequality of power between children and adults compounds the difficulties of an adult researching children. When studying a concept such as dignity it could be all too easy to take the adult perspective on dignity and providing the adult answers to protecting and promoting it in hospitals.

During the Pilot Study there was opportunity to talk and interact with the children fairly easily, either on the ward whilst helping staff with bed making or giving out meals or in the school/play room. However in the Main Study the children had a parent with them for the majority of the time. This meant that opportunities for interaction were less. In the intervening period between the pilot and the main study the notion of family centred care had become the norm:
“Children are viewed as part of a family and are dependent on their parents for physical and emotional care and support. Caring for a child means involving parents and siblings” (Audit Commission, 1993, p.9).

During the interim between the pilot and the main study, caring for the children in terms of their day to day needs, had become the work of the parents, usually mothers. This may have been, in part, a reflection of the different socio-economic status of families in the two sites. In the main study parents stayed by the beds of their children for most of the day. As a consequence, my physical access to the children was difficult and so my ideas of playing with the children and using innovative techniques for capturing their experiences were difficult. Indeed it was impossible to get to the children without stepping over the resident parent! Despite being encouraged by research studies that employed innovative techniques and methods to hear and listen to what children had to say, the reality of the setting for the main study seemed to preclude this.

It was at this point that, I realized fully the importance of understanding the dignity of the child in context. Needing to rethink my approach to an understanding of dignity and the child, led me to realize the importance of understanding the meaning of dignity for all the key participants on the ward. Rather than just the children, I needed to investigate the perspectives of their parents (usually the resident mother) and the staff. This would allow me to determine how dignity was constructed, performed and experienced at a macro and micro level. This approach enabled me to challenge how assumptions moulded and influenced the way dignity was upheld for the children in hospital. Thus by focusing on the experience of the child, I found that first I had to widen my gaze to include the family and staff.

3.3.5 Field-notes.

I used naturalistic observation to study the participants, that is the children, the parents and the staff, their interactions and their meanings in the context of the hospital ward. The nature of qualitative research and ethnography in particular requires the researcher to become immersed in the data to become familiar with the worlds of the participants. These observational data were recorded as field notes.
The field notes for the pilot were mainly written on the ward, in the office, or parent's room taken and written up as soon as possible afterwards. Ely (1991, p. 70) comments on the importance of field notes;

"The log is the data. Detail is everything: only that which is recorded in the log is available for research."

I was conscious to make the notes as detailed as possible, although I found this quite difficult, being used to recording details in brief note form. The ethnographer and symbolic interactionist Erving Goffman (1989, p.131) wrote:

"Write as lushly as you can, as loosely as you can, as long as you put yourself into it, where you say, 'I felt that'...to be scientific in this area, you've got to start by trusting yourself and writing as fully and lushly as you can."

Additional pilot work allowed me to try different ways of recording field notes. When I was at the nursery I took notes while I watched the children and wrote them up soon afterwards. During the school visits, I took no notes on the premises, but made brief notes afterwards and wrote up fuller notes when I got home.

In the Main Study I used a voice recorder for interviews, however, I did not use it to record my own field notes or analytic memos. My voice recorder was particularly small and sometimes children and parents thought it was a mobile phone. I did not want to make my action covert in any way and for this reason I did not make audio memos, but always wrote memos down, so that it was transparent that I was taking notes, rather than using the phone.

Computerised records of data subjects were kept in line with Data Protection Act (1998) and advice sought from the Data Protection Officer at the university. Confidentiality was vital and I took great care when taking notes not to betray the identity of any of the participants. I explained to participants how the information I collected was to be handled and answered any questions they might have had. It was important to bear in mind, at this stage that children may have found it more difficult than adults to challenge what was recorded about them. I adopted a way of coding the children, from the outset, to include their sex, age, and sequential number that I could use in my note taking. In the text I allocated pseudonyms and also took care not to inadvertently disclose the identity.
of a child and his/her family by descriptions in the text. I treated data from staff participants in a similar way.

One of the issues concerning the collection of observational data is that it has to be constructed into text. Berg (2001) outlines a few useful practical hints about recording and using observations as data that I have found useful in identifying features of the field and events that constitute observational data and recording them in order to analyse them. These are:

- Record key words and phrases in the field.
- Make notes on the environment and the sequence of events.
- Limit the time in one setting
- Write up notes as soon as possible after leaving the field
- Write up notes before analyzing them or even talking about them.

Atkinson (1992, p.21) states that the ethnographer needs to be “actively engaged with the texts” both in their construction and their interpretation. He describes the field-note as essentially an open text, from which one can derive alternative meanings. The text, he suggests, is reinterpreted again by the reader as they make sense of the text:

"However much the author may seek to generalize, to compare and to theorise on a grand scale, the work is necessarily grounded in the local. The ethnography is bound in time and place. The ethnography is shaped by the sensibilities and style of the author."

In the field-notes I included descriptions of subjects, including their appearance and mannerisms, dialogue and non-verbal communications and particular events. The latter included special or “one off” events or routine events. The behaviours of those involved and the manner in which the event occurred need all to be recorded (Field and Morse, 1985). As this study progressed, certain events including procedures and practices began to form the focus of my inquiry. These are included: meal times, toileting, cannulation, ward rounds, playing and clinical examinations. As the research progressed alongside data analysis, it was important to structure constant comparative analysis around key events. This not only established typicality of the observation, but also highlighted differences, "negative cases", between situations and individual participants (Berg, 2001, p.256). An example of this, from the main study, was the
observation of medical examinations on children at admission. Staff reported that curtains were drawn and I observed that they were. A negative case highlighted an inconsistency when examinations took place in the Ambulatory Care bay. Using this difference from the usual way of behaving, I was later able to check out its significance. Subsequent observations and focused discussions with staff confirmed that curtains were not always pulled round curtains in the Ambulatory Care bay. I was then able to extrapolate the significance of this finding and offer an interpretation.

For the Main Study, my change in emphasis to the construction and meaning of dignity and children necessitated parents and staff to become more visible and they were acknowledged and brought into the research to a greater degree than in the pilot work. Interviews became an important part of the data.

3.3.6 Interviews

The use of interviews has long been vital in a range of qualitative methodologies not least ethnography and grounded theory. In the pilot study, I used interviews “on the hoof” as a way of learning to see the world and the concept of dignity from the eyes of the nurses and play leaders. These interviews were not audio taped, but recorded along with the field-notes, by hand and later analysed in the same way as the field-notes. Despite their informality, I followed the format of the beginning frame (Appendix 3) and areas of discussion as submitted to the Ethics Committee. Due to delays in negotiating full approval and police clearance to work with the children, I was not able to interview the children until much later in the Pilot. As time was limited I chose to not interview the children, but to use the opportunity as a participant observer and assess the field for future opportunities to reveal the voices of the children.

In the Main Study I interviewed staff, children and their parents in a more formalised way. I was cautious to interview in this way prior to commencement and yet the interview process seemed to alleviate barriers and encourage communication and clarity of understanding that I did not experience in the Pilot Study where I did not undertake interviews in this way.
The interviews with the staff followed a more structured pattern, whereas those with the children and their parents were more narrative. I was especially conscious not to upset the flow of a child talking and attempted to follow their lead where possible. One of my questions was whether dignity changed as children grow up. This example comes from my interview with fourteen-year-old cm14010, who had had numerous and lengthy hospital admissions:

R: ...and do you think that dignity changes as you grow up?
C: (Looking away)
R: Can you remember those early times when you were in hospital, compared to now?
C: Yeah, I can ummm. It was a lot easier....
R: Easier when younger?
C: You know like not, not embarrassing, because the younger, when you get older and you got female nurses looking after you....

This example gives an indication of the more discursive nature of our discussions and the next topic was determined by the child. In this case, we went on to discuss his feelings of embarrassment about intimate procedures being performed on him by young women. At fourteen, he found this a lot more difficult than when he had been younger. He demanded more male nurses.

In contrast, below is an extract from my interview with staff member 4FP, including the same question:

R: And do you think dignity changes as you grow up?
4FP: I don't think dignity, I think your perception of it changes as you get older, more aware, but I don't think dignity should change depending on, you know. Whereas when you are treating someone I think it should be the same whether they are tiny or whether they are older.

At this point, there was a pause and I went on to my next area of inquiry.
Despite these different approaches, I attempted to cover the same issues within each interview to allow for comparisons. I have included my interview schedule (Appendix 3). Ely (1991) sees the separation of structured and unstructured interviews as false, arguing that all good interviews have structure, the difference lies in the way some have a structure that is predetermined and in others the structure is shaped by the process.

3.3.6.1 Interviews with the children and their parents

The pilot work revealed the rich potential offered by the play and teaching staff in gaining access to the children in a setting that promotes self-expression not to manipulate, but to facilitate the interviews and to ascertain the thoughts and feelings of the children.

In the Main Study I recorded 31 interviews with children and their parents. Some of the most successful interviews have been where I have talked with the child and their parent at the same time. This was because the children were often very young and I felt I could better build a rapport with the child and parent if my approach was rather more child/parent centred. By this I mean that I attempted to talk about their experiences in hospital in a way that followed a more natural conversational approach where the choice of direction for our discussion was, to some extent, shared.

Where I had not had the opportunity of talking to parents beforehand, I did not approach children. When children approached me in conversation, I found it difficult to act spontaneously because I did not think they were fully informed as to who I was. Sometimes a child I would like to have talked to was made unavailable on the request of the nurse in charge, even if they have expressed a desire to be interviewed (cf15093).

Adopting the same ‘beginning frame’ for all interviews with children and their parents allowed me to collect details about the participants and it also broke the ice. From there, the interview developed into quite an informal discussion and the data constructed was more narrative in quality than the later interviews with the staff. In interviewing the parent and the child together there is of course the risk that the parent dominates the discussion or the views of the child. On the other hand, they have been able to interpret where necessary and elaborate about particular instances where necessary. I had to guard against striking up a relationship with the mother, that sidelined the child, albeit
unintentionally. The shortest interview lasted just ten minutes with the longest interview lasting over an hour. Two children were interviewed with their parents in their own home, after their mothers had heard of the study and wanted to take part.

Due to the fast turnover of the ward I was not able to return to a child and their parent, except on a couple of occasions and so the interviews were a snapshot in time of how each respondent thought about the meaning of dignity.

3.3.6.2 Staff interviews.

Following a six month period of observation and interviews with parents and children, I undertook interviews with 16 members of staff who worked on the Children's Ward. I chose to interview the staff last as I did not want to understand the experiences of the children and their families before looking at the staff in greater depth. They included:

- 3 senior doctors, who were all paediatric consultants,
- 1 junior doctor (senior house officer), who was in her first year in the specialism of paediatrics,
- 1 physiotherapist specializing in the treatment of children,
- 1 student nurse in the second year of her degree programme to become a children's nurse
- 2 senior specialist nurses, one a specialist liaison nurse and the other a specialist epilepsy nurse
- 1 nursing sister, who regularly took charge of the ward
- 1 matron, who had responsibility for acute children's services.
- 5 staff nurses
- 1 health care assistant, who also had a nursery nurse qualification.

I have enclosed some further detail in my staff data record (Appendix 7).

I recruited the doctors by introducing myself at one of the Educational Half Days¹ and asking them to sign up to be interviewed. I then fixed a time and date with their

¹ Educational half days for medical staff are compulsory. They ensure compliance to continuing professional development and clinical governance. They are held monthly by specialties within the Trust.
secretaries (consultant), or directly on the ward (senior house officer). I used a similar approach with the nurses, introducing myself at a meeting, getting to know them on the ward and then asking them to sign up if they wanted to be interviewed. The physiotherapist and specialist nurses I approached directly when they visited the ward.

The interviews were taped with the permission of the respondent and later transcribed. Interviews took between 14 and 50 minutes. The interview schedule comprised a series of open questions and prompts were given to elicit more information and to clarify. The same topics were covered in the parent and the child interviews. The choice of venue for the interview depended on the respondent. The nurses, physiotherapist and health care assistant were interviewed on the ward in the Adolescent Bay when it was empty. The sister took me through to the locked staff office just outside the ward. The specialist nurses saw me in an office they shared with another and the matron in her own office. One consultant saw me in his own office and the other two in an empty clinic room. The method of arranging an interview and the location related to the position in the hospital hierarchy of the participant.

3.4 The Data

3.4.1 Identifying data

With so much data from participant observation and interviews over a protracted period of time, it can be difficult to "see" the data. At the beginning of the research I found it difficult to identify what detail should be recorded as my senses were almost overwhelmed with smells, sights and noises and feelings. Looking back that data were all so important and more difficult to access once I had grown accustomed to the setting and this window of opportunity to see things for the first time was important. In this section I would like to focus on the way data can be constructed from the field. How data are recognized as such and recorded and the job of interpretation and analysis begins. I will return now to the idea of using strangeness as a methodological device.

3.4.2 The notion of strangeness as a methodological device
"The most difficult part of the ethnographic enterprise is to make the data sound abnormal, sound surprising" (Burawoy, M. 1991, p.294).

One way of becoming specifically aware in a more tangible way is to identify and emphasize what is strange within the data and to use this as a point of further enquiry and analysis. This process can be likened to the idea of wearing tinted spectacles to review the data.

"The less familiar you are with a social situation, the more you are able to see the tacit cultural rules at work" (Spradley, 1980, p.62).

Throughout my analysis of the fieldwork to date, I have found using the notion of strangeness useful as a tool, or methodological device, to identify aspects of the field that warranted further investigation and explanation. As a researcher I had to battle to experience the atmosphere and to see things afresh, not to operate from assumptions and stereotypes, but to suspend them. I have found "the strange" a useful way of defining this.

I have included here an extract from my fieldnotes from the Pilot Study that illustrates just how strange the hospital seemed to me on my first day "in the field". Presenting the text out of context brings into focus some of the strange spectacles of the setting and presents them for analysis:

"The wards are reached through a very long corridor on to which spill visitors, staff, relatives, doctors discussing patients and the patients themselves. There are doors to toilets, more corridors, A&E (Accident and Emergency), wards, shops and operating theatres. Some of the doors have signs which say "Emergency Theatres" and there are people standing around in their theatre greens, very old and ill looking people on trolleys and people who look like your next door neighbour walking around in their slippers and nightwear. It certainly is a slice of life, some of which, particularly young children will never have seen before."

Certainly, hospitals are strange places and, as a researcher, there is value in being able to try for a time to 'keep it strange'. Harry Wolcott (2002) in his key note address, said that ethnographers tried to keep the familiar strange as they went about their research.
Whyte (1955) was one of the first to advocate that social researchers should treat their own familiar cultures as anthropologically strange. Toren (1996, p.102) similarly advises would-be ethnographers to “render strange what we take as given”.

Toren (1996) states that increasingly, ethnographic studies are undertaken “at home” that is in contrast to the traditional model where ethnographic studies were focused upon the exotic. I would argue that this distinction is a false one and that “at home” studies are still foreign in that they still challenge one’s taken for granted assumptions, but the clues are more subtle. Toren highlights that for ethnographers working at home it can be immensely difficult because the participant observer is required to focus upon a culture that they themselves are a product of and “take for granted ideas and practices that should themselves be a focus of analysis” (p.104). This is where the need to “keep it strange” is paramount. Toren describes this as the process of rendering strange what otherwise seems to be perfectly ordinary.

All types of data can be described as strange. A similar suggestion is that the ethnographer should “look for surprises” (Burawoy, 1991). Ely (1991, p104.) urges researchers to listen and to use their hunches and intuition about a situation as long as they recognize it as such:

“It is essential for qualitative researchers to understand that...hunches, insights, directions do not arise out of nothing and that often they are the results generated from meaningful lived experience.”

Types of data that I have considered strange during the course of the field-work has included:

- objects,
- what people say and the way they say them,
- physical space and its use and
- incongruities with cultural/social norms.

On the hospital children’s ward there were many examples of incongruities with social norms. These observations have been particularly informative in exploring how dignity is protected and promoted. Once some of these strange, or out of the ordinary occurrences
and incongruities to social norms have been identified, it is possible to see the way rules are used to 'normalise' the strange and to set the culture of the setting under one's scrutiny. It was revealing to see how the children and their parents in the ward worked to normalise their environment and give meaning to the events that occur around them. For example cm6024 spread out all his personal belongings from home to fill the space of his sideroom. Something that he would not have been able to do in a bay with other children (7.2.1).

3.4.3 The researcher in qualitative research data.

The acknowledgement of one's self and one's own biases in qualitative research in general, is in contrast to traditional quantitative methods. Here the researcher is hidden away and unacknowledged, from the research process, to the writing up of the report.

"In quantitative research, all trace of the production and producer has traditionally been expected to be wiped from the research account writing" (Aldridge, 1993, p. 54).

In qualitative research, reflexivity is essential to contextualise field-notes, and notes can be made about the field-notes as to one's own emotional or physical reactions to what is being recorded. I will discuss reflexivity in more detail when I return to ways of evaluating studies.

Although the self is recognised as important in qualitative research, there is little guidance on how to use insights (Baillie, 1995). The trustworthiness of the research relies on the self-awareness of the researcher and their ability to form relationships with their participants. These are both unverifiable criteria. Thus the way the self is used must be made explicit in qualitative research. James and Whittaker (1998) assert that the researcher should take responsibility for the data collected and in doing so, to connect experience to understanding and make the process of data production and interpretation clear. Using analytic memos are a way of documenting this and ensuring that the voice of the subject is recorded as data and integrated in the text.

I used analytic memos as a reflective tool to record abstract thoughts about the data or in relation to the data. I wrote these in my observation notes as immediate reflections or in my research journal later. They could take the form of notes and or diagrams. Ely
(1991) uses the term "analytic memos" to describe memos that are written about entries in the log or field notes, which themselves become part of the data. These have an important function in moving both the methodology and the analysis forward. Ely (1991, p.80) suggests that analytic memos should be recorded:

"Like conversations with the self about what has occurred in the research process, what has been learned, the insights this provides, and the leads these suggest for future action."

Christina Toren, a renowned ethnographer, states simply that if you feel angry write it down. If you are amused, then write it down. Kleinmann and Copp (1993, p.19) too stress the importance of including one’s emotional reactions during the research and analysis, they state:

"By leaving out analytic commentary (especially when it is emotional), the data take on an obdurate quality. The notes become recorded facts rather than constructed understandings."

Kleinmann and Copp (1993, p. 42) highlight the need to include uncomfortable feelings, the exclusion of which they argue, would amount to ignoring data. The system of "bracketing" allows the researcher to record, but keep separate their own assumptions, feelings and preconceptions from the field notes. From there Kleinmann and Copp (1993) advocate re-reading the field notes and making analytic memos. They promote the use of "notes on notes" as a way of elaborating on field notes, and incorporating emotional impact into the analysis.

3.5 Data Analysis

In grounded theory analysis runs simultaneous to the collection of data. The notion that data analysis is not distinct from its collection is an important feature of an ethnographic approach, not only one that uses grounded theory. This is counter to a positivist tradition of data collection and analysis being two distinct stages. There is a subtle variation in the way this is interpreted by researchers. Pidgeon (1996, p. 79) writes: "Data analysis can (and ideally should) proceed as soon as sufficient material is collected to work on."

However, even at the stage of observing and semi structured interviewing, decisions are
made by the researcher, on the basis of the emerging data, as to the direction of enquiry to follow next.

In keeping with grounded theory, the collection of data and the analysis have run concurrently. This approach to data collection and analysis is known as constant comparison or comparative method. Charmaz (2006, p.23) outlines the integral nature of this approach to grounded theory in ethnography as it enables the researcher to:

1) Compare data from the beginning of the research, not after all the data have been collected.
2) Compare data with emerging categories, and
3) To demonstrate relationships between concepts and categories

A subtle difference in approach is described by Fielding (1993) who describes the similar process of “sequential analysis” where data begin at data collection and in between periods of data collection, the researcher “steps back” to reflect on meaning and to redirect the research and further observation. I found that, in practice, I needed to spend some time away from the ward in order to catch up with transcribing and analysis. This did on occasion break continuity with the children, staff and parents, nevertheless it gave me space to gather my thoughts in a more creative way. Hammersley and Atkinson (1995) advocate the need for ‘space’ suggesting that that there must always remain some part held back, some social and intellectual ‘distance’. “For it is in this space that the analytic work of the ethnographer gets done” For this reason I found it necessary to take time away from the study site to read, transcribe and reflect upon the research experience.

Although I found it useful to evaluate and interrogate the data soon after writing it up, I also found it helpful to return to observation notes and transcripts sometime after the events. I found time to be valuable in order to lose some of the familiarity that breeds blindness in the researcher and the space and opportunity to reread and reflect on data again. This distance in time can free up some space for further analysis and interrogation of the data to take place.

I will return to the notion of space, and time to be allowed in order for work to be done, in the Findings section. In Chapter Six, the nurses describe how they "moderate" their
approach in their interactions with the child and their family. It is also a concept that is used in therapeutic relationships and is the integral to the notion of emotion work.

3.5.1 Theoretical sampling

The goal of a grounded theory is to develop a conceptually rich and grounded account where sampling is driven by the emergent theory. This is known as theoretical sampling and is a feature of grounded theory and the comparative approach. Theoretical sampling is used together with constant comparison and involves the active sampling of new cases as the research progresses (Pidgeon, 1996). In theoretical sampling choices of cases are made on the basis of the emergent theory. An example of this would be when a five year old boy made a comment about wearing a theatre gown. I speculated that his view, in part, might be a reflection of his age or sex and so I actively listened for views about operating gowns from other boys of his age and also girls and older children to inform the theme.

I found that I was in a continual flux between analysis and enquiry. Despite progressing in a systematic way through data collection and analysis, I found it frustrating to be unable to define findings when the research was in progress due to the shifting patterns of themes and categories. It was reassuring to note this comment from Kleinman and Copp (1993, p. 4) who stated:

"Field researchers who work inductively dread their colleagues' innocuous query 'What are you studying, and why?' Then we know we cannot give a satisfactory answer: 'I am looking at the effect of X on Y'" (p.4).

3.5.2 Interview analysis

At the time of each interview, I recorded a few key points. Sometimes this was during, but more commonly immediately after, the interview on what I was thinking and feeling and the atmosphere of the interview. Occasionally I did not register reactions in myself until sometime later, but I tried to record them all when they came to mind.

I transcribed all the interviews myself. I found it useful to hear again the voice of the respondent(s) as this reminded me of the context of the interview and stimulated a visual
memory. I transcribed the interview verbatim then read it through once to get the flavour of the conversation. I experienced a dilemma at this stage of transcription, concerned with the way to best record the “real” interview. I felt that something of the essence of the interview and the relationship between the participant and the interviewer could be lost by the time the interview appeared as text on a piece of paper. My dilemma was how to record this essence, or music behind the words, that does not easily translate to written text. As a way of overcoming this, I reflected on interviews as one might a therapeutic or counselling interview and tried to consider “the relationship”, and asked myself “What else is going on aside from the words?”, ‘What are the two parties thinking and feeling?” “What is my body and theirs telling me about how we are?” “What else is being communicated by not saying it?” These are the things that could be difficult to tune into and record, sometimes because of the environment where the interviews are undertaken and at other times because of time constraints. Despite my concerns of losing such data, I uncovered more material from reading the text “cold” as a way of picking up things that were said, possible nuances that were lost, or even obscured in the heat of the interview itself.

Following transcription I continued the process of analysis of the interviews by identifying themes. I began with the staff interviews as they had followed a more predictable course through the questions and were more homogenous in their structure than the interviews with the children and parents. I chose two interviews to begin this analysis. I selected these two because of some of the similarities of the respondents: they were both nurses, one (1MN) in the process of qualifying and one (7FN) having been qualified for two years. However, these two interviews also demonstrated key differences in the meaning of dignity and in the way the respondents answered. To illustrate this, I have included extracts diagrammatically, from these two interviews as Appendix 9: “Extract from the interview with 1MN” and Appendix 10: “Extract from interview with 7FN”. By starting with the comparison of two contrasting interviews I was able to identify areas of difference that could warrant further exploration in subsequent interview analyses. 1MN describes his understanding of dignity in children using case examples. He includes a diverse range of concepts relating to their dignity including: professional power over children (comment p12, bullying), staff following their own agenda (comment p15) and working to establish individuality of patients (comment p20). 7FN gave pragmatic responses while demonstrating her understanding such as “giving privacy” comment p1), drawing
curtains (comment p7), giving time (comment, p9). 1MN gave very full responses to my questions and his answers to my questions were enmeshed in the replies he gave. 7FN, however, gave short succinct responses. Respondents comments were later coded as red for indicators, green for constructs and black for theoretical concepts or themes reflecting their levels of abstraction (3.5.3). After summarizing the themes from these two interviews, I moved on to the other interviews. Next I examined the consultant interviews (3), then the senior house officer (1) and physiotherapist (1), then the senior nurses (3) and then the staff nurses (4) and health care assistant. After identifying themes from these summaries I drew them together to create a framework on which to build the analysis.

I continued to work on these themes by constant comparative analysis, to conceptualise the meanings dignity had for this staff group. Constant comparative analysis describes a process of continually identifying and sorting indicators in data, both within a source and between data sources (Pidgeon, 1996). Indicators are put in juxtaposition with others and their comparisons promote emergent constructs. This process continues throughout the research from inception to theory development. As analytic properties of constructs become more defined, so the researcher can make links back to the data. This method of clarifying similarities and contradictions promotes the credibility of the research.

I continued the analysis of the interviews with the children and parents in a similar way to those of the staff. The nature of the interviews with this group was more varied than the staff interviews that tended to follow a clear structure and trajectory. The interviews with the children and their parents were more narrative in style and based loosely on my questions. As a result some sections reflected little of how the children and their parents perceived dignity. Each interview was precious as it was very rarely possible to go back and check the meaning of something that was said because of the turnover of the ward. Much of the data were very rich and emotive and very clearly relevant to the meaning of dignity to the child and their parent. I started the analysis by reading and rereading each interview.

3.5.3 Manual coding
Rather than using computer software such as NVivo® for the coding and analysis of the data, I chose to code manually. This was for both the pilot work and the main study. I experimented in the best way of identifying the different points made by the respondents. I settled finally for using highlighter pens to record points of interest, summarizing key words or points (indicators) on the left of the page and any interpretations, or thoughts to myself on the right. For the majority of the interviews I made a summary front page that included any moments or comments that particularly stood out from the interview, or connections to other interviews and observations.

I used three levels of categorisation in my analysis, and used colours red, green and black to denote the level of abstraction. Thus I used red for developing themes/codes (indicators), I used green for theoretical concepts (constructs), and black codes for key concepts that contribute to the development of theory. Red also included observations that caught my eye, but not in a way that directly seemed to relate to dignity at the time. I was sometimes able to develop these indicators later and incorporate them at a higher level of theoretical abstraction. An example of this would be drains, that at first had no particular significance to my understanding of dignity, yet became important into developing first the construct of body boundaries and later the key concept of the embodied child. In Figure 5 (page 99), I have presented a diagrammatic reconstruction of the analytic process.

Following coding, I clustered themes together. The various categories were incorporated into thematic families, where links were made to other codes and concepts. As I have described with the example of drains, categories changed and developed as time and analysis progressed. The process of developing a conceptual framework was fluid and dynamic. I used spider diagrams and Post-it® notes to structure and restructure my developing ideas. Post-it® notes allowed me to arrange and rearrange the groupings. I included the interview reference of each code in the corner of the Post-it®. I found this to be the quickest, easiest to manipulate and most visual representation. At this stage I recorded my developing ideas on the computer, using Word documents and folders to sort the data, placing the information from the Post-it® notes, always with their originating identifying code, into documents. This enabled me to record and eventually write up more efficiently.
Dignity and the Child in Hospital.

Diagrammatic representation of my analytic process

**Indicators**

- **7FN**
  - Drawing curtains round

- **7FN**
  - Observing patient

- **1MN**
  - “Turn power off”

- **1MN**
  - Asserting through disruption

- **Cm4052**
  - “I always keep still”

**Constructs**

- **7FN**
  - Doing dignity

- **7FN/1MN**
  - Passive patient

- **7FN/1MN**
  - Professional power over patient

- **1MN/Cm4052**
  - Active patient

- **Cm4052**
  - Emotions work of child

**Key concepts**

- **7FN**
  - Performance of dignity

- **7FN/1MN/Cm4052**
  - Power

- **Cm4052**
  - Emotional Labour
Indicators could become constructs as analysis progressed and it became apparent that their significance had greater in the generation of theory. On occasion I used direct quotes such as "turn the power off" from Appendix 9 and incorporated as a construct in the analysis (figure 5). This was in order to maintain the intensity of the statement and in some cases to become a metaphor, in this case, the power professionals were able to use over their patients. Although I coded interviews by hand I have coded the transcript extracts diagrammatically in the appendices for clarity. I have taken a sample of analysis from the three extracts of transcripts included as appendices 9,10 and 11 and demonstrated, diagrammatically, how themes were clustered and reconstructed through levels of abstraction in figure 5. This extract from the data analysis demonstrates how the key concept of power was reconstructed from the data of three interviews. By systematic recording of the origins of indicators and theoretical concepts, I was able to go back and forth through the data as the analysis progressed and give clarity to the process of analysis.

As the analysis progressed and more data were analysed, so some of the original indicators and constructs were abandoned, or at least diminished in significance. An example of this was the construct of "favourite" that arose from the Pilot Work (4.12.2), but had little corroboration in the Main Study. "Favourite" was a term used to describe a fifteen month old, developmentally delayed and oxygen dependent, who had been resident on the ward since birth at 24 weeks gestation. He had become the "pet" of the ward, living in a glass sided cubicle opposite the nurses station. I speculated the death of his mother and the absence, at the bedside, of his father had had the effect encouraging his "ownership" by the ward staff. His care provoked questions about the nature of dignity, but such treatment of children was not so obviously observed during the main study and although elements (indicators) reappeared, the construct of favourite tempered.

I found that grounded theory required me to be able to focus on the detail and yet keep in mind the whole and at times it was a challenge as I moved back and forth through data analysis. It was like taking a slice through an apple and examining what I saw and then standing back to view the whole, then repeating the process once again and again until the whole structure was known to me. Eventually these themes became eleven headings that were then reduced to just eight. This process required repeated
formulations and reformulations of the analysis in order to construct a coherent and meaningful theory.

3.5.4 Using symbolic interactionism as a theoretical framework

I have incorporated the lens of symbolic interactionism (Blumer, 1969) within the grounded theory as it positions the participant as actor and his or her actions as symbolic. Symbolic interactionism is concerned with the meanings of the interplay and gestures and between the actors within a social context, for example the hospital ward. Symbolic interactionism postulates that individuals act on the basis of the meanings they attribute to events and to the actions and reactions of others. It is a theoretical perspective that assumes "people construct selves, society and reality through interaction" (Charmaz, 2006, p.189). The context is essential to this interpretation (Benzies and Allen, 2001). Charmaz (2006, p.169) describes how concepts of symbolic interactionism inform her world view and influence what and how she sees. These concepts remain in the background until they become relevant for analytic problems. Charmaz describes how the researcher can put sensitizing concepts and emerging codes from the data to work in a theoretical framework. This helps to position the study in relevant disciplines and discourses.

Goffman (1963; 1971) builds on the work of symbolic interactionists and describes the rituals of interaction and social acceptability and unacceptability. He takes a dramaturgical approach to describe altered behaviour patterns in institutional care, emphasizing meaning and performance with metaphors from the theatre. I found this perspective very useful particularly in exploring the performance of dignity, as I have described in my findings chapters. Before presenting the findings, I will now discuss some of the criteria by which a qualitative study can be evaluated.

3.6 Evaluating the methodology.

Methods of evaluating research for quality and rigor need to be tailored to the nature of the study. To transfer directly methods designed for use with quantitative methodologies, is not appropriate (Baillie, 1995). Traditional measures used to evaluate quantitative research, such as validity and relevance, must be first operationalised in such a way as
to take into account the distinctive goals of qualitative research, such as ethnography and grounded theory (Mays & Pope, 2000). There are many variations of the terms used to evaluate qualitative studies. Glaser (1978, p.4) describes the criteria of fit, work, relevance and modifiability as useful in evaluating grounded theory. These criteria have been modified by Charmaz (2006) who describes: credibility, originality, resonance and usefulness. In determining the value of ethnography, O'Reilly (2005) describes the measures of representativeness, validity and reliability. Hammersley (1998) provides a comprehensive discussion concerning the nature of ethnography and ways of evaluating relevance, replicability, validity and scientific status of ethnography.

In this section I will discuss four ways of evaluating a qualitative study such as "Dignity and the Child in Hospital" relevant to ethnography and the principles of grounded theory. I have adapted the model first described by Guba and Lincoln (1981) and then Sandelowski (1986). The four terms they adopt are "truth value" (credibility), "applicability" (fittingness), "consistency" (auditability) and "neutrality" (reflexivity). I have used the alternative terms credibility, fittingness, consistency and reflexivity. With the exception of reflexivity, I have extracted these terms direct from their work, but use them instead as they are terms also used by other authors. My choice of reflexivity over neutrality is a reflection of the centrality of self in the process of research, not as neutral but as an active agent in ethnography. It is reflexivity that I will describe first.

3.6.1 Reflexivity

As well as observing and noting the 'other', intrinsic to contemporary qualitative methodologies in general, is the presence of the researcher as author of the text. Ethnography has been described as a craft, thereby acknowledging the craftsperson and their way of working in the product - an embodied product (Rachel, 1996). In ethnographic research, the self is the instrument by which the focus of inquiry is selected and the study undertaken, with all its own biases, filters and interpretations. As researchers, self-reflexivity enables us to examine our own motives, biases and beliefs when undertaking research. "Reflexivity is the capacity to reflect upon one's own actions and values during the research, when producing data and writing accounts, and to view the beliefs we hold in the same way we review the beliefs of others" (Arber, 2006, p.147). Reflexivity establishes the integrity of the researcher.
The level to which I, as the researcher, have been reflexive in my account can be used as a measure of the quality of the study. This recognition of the self in qualitative research in general, is in contrast to traditional quantitative methods. In the latter, the researcher is hidden away, unacknowledged, from the research process, to the writing up of the report:

"In quantitative research, all trace of the production and producer has traditionally been expected to be wiped from the research account writing" (Aldridge, 1993, p54).

In qualitative research, reflexivity is essential to contextualise field-notes. Annotations can be made alongside the field-notes as to one’s own emotional or physical reactions to what is being recorded. The notion of trustworthiness is defined by Baillie (1995, p.17) as relating to “the extent to which the data provides insights, knowledge and understanding of the meaning attributes and characteristics of the people under study”. The trustworthiness of the research relies on the self-awareness of the researcher and their ability to form relationships with their participants. These are both unverifiable criteria. Although the self is recognised as important in qualitative research, there is little guidance on how to use it (Baillie, 1995). Thus the way the self is used must be made explicit in qualitative research. Ely (1991, p.94) then suggests that we ask of ourselves to stimulate reflexivity:

“How adequately did I represent what I witnessed?” and “What’s the match between my vision and those of the people I studied?”

Analytic memos are a way of documenting this and ensuring that the voice and questionings of the researcher is recorded as data and integrated in the text.

3.6.2 Credibility

I have used the term credibility rather than truth value. Sandelowski (1986) discusses her measures of worth in research, saying: “Truth is a much more elusive goal” (1986, p. 30) in qualitative research. She goes on to say “Truth is subject-oriented rather than researcher defined” and “truth value generally resides in the discovery of human phenomena or experiences as they are lived and perceived by subjects, rather than in the verification of a priori conceptions of those experiences”. However in ethnographic
research there are many different truths in a given context. As such I put aside her use of truth value in preference for the more pragmatic credibility.

Credibility is described elsewhere as internal validity. Sandelowski (1986, p.29) states that "A research instrument is valid when there is confidence that it measures what it intends to measure". As I have described above, rather than validity she adopts the term truth value. Nevertheless truth value or credibility encompasses other explanations of validity such as Smith's (1996) description of validity as implicit when data are simultaneously collected, handled and analysed to shape ongoing data collection, and to develop and confirm working hypotheses. This is a definition with particular relevance to grounded theory.

One way of checking out the credibility, of the data is to present them back to the participants for their verification. This has been endorsed as a method that promotes both an equality of researcher and participant and allows for the co-construction of the data. Participant checking in this study was not undertaken, although I did check my understanding of what they had to say during the interview process. I did not consider it valid to request feedback on the emerging data after the participant was removed from the temporal and physical context. In this study, participants were in and out of the ward very quickly and I did not maintain contact. However I did let participants know that I would be reporting my findings back to the ward with the intention of making my findings available to staff and patients.

Gaining insights into the perspectives of the children cannot rely upon their responses in an interview situation alone. As O'Reilly (2005) warns “Always remember that they may be answering what you want to hear, or even what they want you to hear.” The responses of the children were no doubt influenced by my adult presence and by the presence of their parent. By using a range of opening questions and following prompts as well as observing the child on the ward, I improved the credibility. I found that when investigating a concept as intangible as dignity I had to take care in choosing language that facilitated discussion around dignity and its associated meanings and not something else. This was of particular importance with the children, but also with adults who found describing their understanding of dignity difficult or challenging (see also my discussion of privacy in Chapter Six, 6.2.1; 6.10.3).
On occasion respondents would give more information and insight after the recorder had been turned off. This occurred after an interview with a member of staff and, although I could not use her later words verbatim, I made notes that I could use to verify her comment and position during the interview.

Qualitative research is credible when it presents a faithful representation of the experiences of its participants. This is in turn is dependent upon the researcher being able to recognise their own experience in terms of their own history, motivation, behaviour and emotions. This in turn relies on a high level of reflexivity.

The process of research is as important as the outcome. It is striking that the promotion of the phenomena under investigation, that is dignity, involves concepts such as the preservation of self respect, informed consent, privacy, and freedom from humiliation, that in turn, are all integral to the research process. For this to occur, the researcher must take responsibility for the data collected and in doing so, to connect experience to understanding and make the process of data production and interpretation clear (James & Whittaker 1998).

3.6.3 Fittingness

Ethnography, as in other qualitative methodologies, emphasises the study of phenomena as they occur in their natural setting without the demand for the control of variables. Fittingness, applies in this study to how the findings were grounded in the fieldwork and the experiences of the participants. The findings and theoretical summations must “fit” the data from which they are derived. Such findings should also “fit” other contexts and be meaningful and congruent to the reader of the research in terms of their own experiences.

In qualitative research in general, samples are not representative in the quantitative sense. In this study the ‘pool’ from which my sample was selected was defined by their presence on the ward. Further theoretical sampling allowed me to select individuals on the basis of the emerging themes. “Representative” in terms of qualitative research can
be used to refer to the data and its representativeness to the sample, rather than the sample being representative of the population from which it was drawn.

As with other qualitative methodologies, ethnography depends upon human experience. In terms of validity, it was important for me not to overweight the perspectives of those with the most vivid stories to tell and my resultant theories fit with the data.

3.6.4 Audit Trail

A clear audit trail can demonstrate a consistency of method from data collection. "Auditability" is a term coined by Guba and Lincoln (1981) to apply to the criterion of rigor or merit in qualitative research relating to the consistency of findings. The audit trail demonstrates the decision making process from beginning to the end of research and renders a study auditable by another researcher. This is important in a research study such as this that was inductive and iterative. In retracing links one can establish how the conceptualisation is embedded in the process. The demonstration of a clear process can lead another to form comparable conclusions. In order to maximise the auditability of my research, I have constructed the thesis in such a way as to give clarity to the process I adopted and my decision-making along the way. Appendices 1-13 give additional evidence of my research process. I have evolved the structure of the thesis with auditability in mind. Sandelowski (1986, p.31) notes: "A useful way to view researchers in qualitative inquiry is as subjects in their own studies" This allows researchers to position themselves as separate from the researched and to acknowledge their own part in the research. In light of this I have presented a third of my findings from my own perspective of events in the initial chapter in the Findings section.

3.7 Summary of Chapter Three: Methodology

I have, in this chapter, discussed my world-view and epistemological position. I have discussed first ethnography and then grounded theory and their applicability to this research on dignity and the child in hospital. I described the fieldwork from the points of access with particular attention to describing the role I chose to adopt as researcher.

I explored some of the ethical and practical implications of undertaking qualitative research in general and specifically with children in hospital. These include power
relations in the researcher/participant relationship. In so doing, I have touched upon the role of the researcher in researching sensitive issues in a way that does not threaten the privacy and dignity of participants and ensures their protection from harm. I described some of the practical dilemmas I encountered when undertaking this research with children and reflected upon how their voices were heard and constructed as data in this research.

The idea of promoting dignity in children is beset with ethical issues, not least because we need to advocate for the person we see before us and the one they will become. The adult should not look back and feel humiliated by the memories of their treatment as a child. Likewise, the research process needs to be undertaken with ethical considerations paramount.

In my first draft of the thesis I put a section concerning the ethical issues of undertaking qualitative research with children as an adjunct to the main methodology chapter as a way of emphasizing the particular issues pertinent to research with children and some of the challenges I faced during the course of the research. In subsequent drafts I reinstated ethical issues to be integral to the chapter. This was in recognition of the requirement to work in an ethical way throughout the research process. As well as exploring some of the more established dilemmas of undertaking research with children I sought to elaborate on my own particular areas of ethical concern in attempting to understand the meaning of dignity for the research participants, in particular the children.

I have made explicit my methods of recording field-notes and interviews, using appendices to evidence these claims. I have explained how I identified and recorded data and developed themes through concurrent collection and analysis of the data.

Finally, I have given an overview of how a research study such as this can be evaluated using the four factors of reflexivity, credibility, fittingness and auditability.

Having introduced my research, presented a review of the literature and discussed my methodology and research process, in Chapter Four I have reported on my pilot work. In chapters Five, Six and Seven I present my Findings from the Main Study. These three chapters represent:
• The voice of the researcher
• The voices of the staff
• The voices of the children and their parents.

Each chapter is subdivided into the themes that I constructed from the data. My intention of using the same headings in each chapter was to draw out the more subtle differences in meaning and interpretations of the staff, children and parents and myself as researcher/observer. Where to position myself as researcher in the analysis was difficult. In the end I have included the analysis of the observational data together with my reflections of the research process and my part in this process in "The Voice of the Researcher."
Chapter Four
Pilot Work

4.1 Introduction

In this section I have outlined the pilot work I undertook prior to the Main Phase of the study. As there had been no previous empirical studies that focused on children and dignity in hospital, pilot work was essential in order develop my methodology and determine the feasibility of my proposed approach. The pilot work comprised:

4.2 An ethnographic study of two children's wards within a District General Hospital of a deprived urban area.

4.3 Additional pilot work.

4.3.1 Visit to a children's hospice.

4.3.2 Observation at a school.

4.3.3 Observation at a nursery

4.2. An ethnographic study of two children's wards within a District General Hospital in a deprived urban area.

Report of the Pilot Study
October 1999(2)

4.2.1 Aims and Objectives

The main purpose of the pilot study was to obtain essential information prior to the main phase of the study, planned for 1999/2000. A period of participant observation was arranged in order to determine the most suitable methodology to apply to my research question. I defined four objectives for the pilot:

- To determine the feasibility of undertaking an ethnographic study of dignity and the child and, in particular, the role of researcher as participant observer in this context.

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This pilot study formed the basis of: Reed, P. Smith, P. Fletcher, M. and Bradding, A. (2003) "Promoting the Dignity of the Child in Hospital" Nursing Ethics 10, 1, 67-76.
• Assess the appropriateness of the ward setting for such observation.
• Confirm the suitability of the proposed age range for the main phase of the study that is 3-11 year olds.
• Begin to explore the potential tools for determining the thoughts and feelings of the children through participant observation, without the need for them to write or respond to formal questionnaires.

In addition, I hoped that the pilot study would provide the opportunity to establish the best times to observe the children, which activities to observe, the role of the researcher, the suitability of time and/or activity based data collection and any other insights into the dignity of children.

4.2.2 Methodology.

In order to explore the subjective meaning of dignity in the child, I adopted an ethnographic approach. In keeping with this, the methodology is iterative and evolving with the way forward being determined by what has gone before. In adopting an ethnographic approach I hoped to gather and interpret the children's subjective experiences of their hospital stay and their impact on their personal dignity. The main method was participant observation. In addition, undertook some interviews and some analysis of documentary evidence. I used grounded theory to interpret the data and to start to develop hypotheses about the nature of dignity. Grounded theory seemed appropriate to apply to this study as previous research into this area was sparse and the knowledge base undeveloped (Field and Morse, 1985). This was a limited Pilot Study and a full conceptual analysis and theory development was not the main aim, but I hoped that a review of my findings would lead to a better understanding of issues surrounding the nature of dignity and children in hospital.

Key to this pilot work was identifying the most appropriate researcher role. During the initial stages of participant observation, observations of the environment, the main players: the children, their families, the nurses, play leaders and doctors were vital. In keeping with the essence of ethnography as the emic perspective (Fetterman, 1989), I sought the insider's perspective, or in this case the child's perspective. In order to understand this, I wanted to keep my role as researcher close to the children, but remain
congruent as an adult. I attempted to adopt a level and style of involvement and participation that was appropriate and acceptable on the ward. Peberdy (1993) asserts the requirement to be “focused and proactive as well as participative and immersed in the rhythms of everyday life”, thereby combining involvement with detachment. I wore a tabard, worn by the health care assistants and play staff and helped by making beds and giving out meals.

I used no audio taping but made notes in a notebook. Instead I used interviews “on the hoof” as a way of learning to see the world and the concept of dignity from the eyes of the nurses and play leaders. I also collected documentary evidence, such as the mission statement of the ward and the information given out to parents and the children. I detailed this information in my field notes. These field notes were mainly written on the ward, in the office, or parent’s room taken and written up as soon as possible afterwards. The field notes descriptions of subjects, including their appearance and mannerisms, dialogue and non-verbal communications and particular events. The latter may include special or “one off” events or routine events. As the study progressed, certain events including procedures and practices began to form the focus of my inquiry. These included: meal times, toileting, washing, dressing, playing and clinical examinations.

4.2.3 Preparation

Prior to the study, ethical approval was sought and granted by the Local Regional Ethics Committee (LREC). This included the submission of an application form together with the Information Sheets and consent forms I intended to use for the study, followed by an interview with committee members. The committee had a lot of questions about the study which I had stressed was a pilot. Their queries centred mostly around the notion of an evolving methodology, rather than going into the field with a set of predetermined questions to support or refute a hypothesis.

I notified the data protection officer in advance of the study, as I would be keeping records on computer. I also sought police clearance because the nature of my study would bring me into contact with children. Despite this being requested well in advance of the proposed start date, clearance was not received until after I had completed the pilot phase. Police clearance was not requested by either the ward manager or the
LREC, but was seen as good practice by the university. Since the Beverly Allitt case where four children were murdered and nine others injured by the nurse looking after them (Clothier et al, 1994), concern over who has access to children has led to the tightening up of procedures for those who wish to work with them. The lack of clearance meant that I restricted myself to accessing the children only where I could be supervised. This led to me, the observer, in turn being observed and the behaviours of the children, who I had come to study being the subject to a double witness. This meant that I was unable to fulfill all the objectives of the pilot study, which I shall discuss in more detail later.

In order to determine the precise role that I would adopt in the research setting, I needed to consult the gatekeepers including the Clinical Nurse Manager (Acute Paediatrics), the Head of Education within the hospital and the hospital ethics committee. The pilot study comprised a period of participant observation, of eight days spread over a month (April 21 - May 12). Time was built into this period to enable me to reflect on my observations and to document my findings. I negotiated my role with my supervisory team and the Clinical Nurse Manager (Acute Paediatrics) prior to the pilot study. I visited the ward on three separate occasions, 7 December 1998, and the 11 and 18 March 1999. After lengthy discussions, it was agreed that I should work as a volunteer, spending some time with the nursing staff and some time with the teaching and play staff attached to the wards. I wore a tabard over my own clothes rather than taking a uniform. I wore a name badge and my I.D. from South Bank University.

I had hoped to meet with the staff prior to starting on the ward in order to tell them about my research, establish a rapport and to answer any questions and allay any fears that they may have. I was well aware that some of the key staff may feel threatened by my presence, or their practice judged. However, meeting the staff prior to the start of the pilot was not possible and I was forced to “enter cold” into the field. I did however give some information to the Clinical Nurse Manager (Acute Paediatrics) and the Head of Education for distribution or discussion with the staff.

I was keen to be upfront with staff, parents and patients about why I was on the ward and displayed an information sheet in a prominent place on both wards. In an attempt not to create additional barriers, I decided to take just a notebook and pen with me on
the ward, rather than a tape recorder, or standardised questionnaires. I attempted to visit
the wards at different times, for example the morning, afternoon/early evening and on a
Saturday.

I made myself brief notes on the ward and wrote these up later the same day. These
handwritten notes were later put on to computer. Although I was able to collect a
considerable amount of data in this way, detail was nevertheless lost to imperfect recall.
Confidentiality was maintained by changing the names of the individuals.

For the purposes of reporting, I sorted my records into categories and later
subcategories. I did this by hand using a pair of scissors and sticky tape. This was
adequate for the amount of data I had to sort, but may have been unmanageable for
larger data sets. Once the data had been categorised in this way, I wrote text to make
sense of the data and to start to interpret and develop hypotheses. This is in keeping
with the grounded theory approach, as first described by Glaser and Strauss (1967).

I will now describe some of my findings in the categories I have created, before going on
to discuss implications for theory development and for the next phase of the study.
Responses by staff are coded to indicate their role on the ward and pseudonyms
assigned to preserve anonymity.

Glossary of Codes

CA - Care Assistant
HCT - Home Care Team
PS - Play Staff
SN - Staff Nurse (General nurse)
SN (Paed) - Staff Nurse (Children’s Nurse)
Sr. - Sister
SSN - Senior Staff Nurse
St. N - Student Nurse (General nursing)
St. Nurse (Paed) - Student Nurse (Children’s Nursing)
T - Teacher
4.2.4 The environment

A large acute provider unit was selected in X Healthcare Trust for the pilot study. The hospital had 680 beds, and one of the busiest Accident and Emergency Departments in the country, serving a local community with a diversity of ethnic, age and socio economic groups.

This hospital had two children’s wards: Lloyd and Beauchamp (pseudonyms). At the time of the pilot study, Lloyd ward took children for planned operations and medical day care, such as those undergoing investigations and those who were receiving chemotherapy as an outpatient. Beauchamp took all the acute admissions. Prior to the Pilot Study there had been moves to merge the two wards with a view to building a new purpose built department in 1999. During the course of the study, however, these plans were shelved. This left the staff attempting to provide an integrated children’s service over two wards with considerable physical restrictions for staff, patients and their families.

This hospital was chosen for the pilot study because of its affiliation with a university and its role as a District General Hospital and teaching hospital, serving a large mixed population, including a large number of children.

I made notes on my first impressions of the hospital when arrived on Day One of the pilot, 21 April 1999:

Hospital X is a sprawling hospital made up of modern and very old buildings, providing a contrast between the “hi-tech” and the crumbling and decrepit. The children’s wards are reached via the main entrance of the older block. Past the entrance runs a very long corridor on to which spill visitors, staff, relatives, patients, nurses and doctors discussing patients. There are doors to toilets, more corridors, Accident and Emergency, wards, shops and operating theatres. Some of the doors have signs, which say “Emergency Theatres”, and there are people standing around in theatre greens. Very old and ill looking patients on trolleys and people who look like your next door neighbour walking around in their slippers and nightwear. It certainly is a slice of life, some of which many people and particularly young children will never have seen before. The entrance to the children’s wards is down a flight of stairs at the ominous sounding Junction Thirteen. Each ward comes off at right angles from the main corridor and is accessed through pressing an intercom and pushing the door when answered.
On entering Beauchamp Ward (Figure 6, overleaf) one walks past a couple of offices on the left, the linen room and the parents’ room on the right, followed by the kitchen. High up, on the walls, are collages depicting hospital scenes that have been made by the hospital school. Before reaching the ward, on the left there is a treatment room, followed by cubicles and then the nurses’ station on the left. The ward opens out to a small bay of six beds and to the left is another bay of four beds, with access to the outside play area. The ward is very hot.

Although the nurses’ station is centrally placed on Beauchamp, it is difficult to see and be seen from this point due to the layout of the ward. There are two high stools at the station and the phone seems to be constantly ringing or in use. At break time the nurses go on to one of the offices on Lloyd Ward.

Beauchamp Ward is particularly cramped and areas for play are very limited unless children are well enough to go to the schoolroom and play area on Lloyd Ward (Figure 7, overleaf). Space for toddlers is particularly limited.

At the time of my arrival to the ward, the staff had been expecting the wards to be redeveloped to provide a purpose built children’s block. However, during the course of the pilot it became apparent that this was not going to happen. The pilot study thus coincided with a difficult time on the ward, not least because both wards suffered from an acute shortage of staff, with a third of the nursing workforce being employed on an “ad hoc” basis through an external agency. At the time of the Pilot (1999), there was a nationwide shortage of nurses in the UK and difficulties with retaining staff (Finlayson, et al, 2002). Staff employed through an agency did not necessarily have any prior knowledge of the hospital. Working for just one shift at a time limited the continuity of the workforce and care. Agency staff are checked for current registration and although every effort was made to employ children’s nurses, this was not always possible.

There were no soft chairs on the ward, apart from in the parents’ room. On one of my visits prior to the pilot study (7 December, 1998), I noted just how uncomfortable and unhomely the ward appeared. All the children had televisions by their beds, both on the
Figure 6: Beauchamp Ward

Figure 7: Lloyd Ward.
ward areas and in the cubicles. These were often left on during the day. Toys were put out on tables on Beauchamp during the day.

Some staff seemed well aware of the physical limitations of the ward. CA. Jan commented on what she would like to see made available to the children. “I would like to see a soft play room with lots of shapes and stuff, where toddlers can go and let off steam.” She referred also to those with special needs.

As a visitor to the ward, I found the uniforms confusing, despite being familiar with medical and nursing hierarchies. Below is a key to the uniforms worn by staff at the time of the pilot:

- Clinical Nurse Manager: - own clothes
- Ward Manager: - dark blue uniform (sometimes own clothes)
- Home Care Team: - own clothes
- Teachers: - own clothes
- Play Staff: - own clothes with tabard
- Sister: - own clothes with tabard
- Senior Staff Nurse: - white uniform with red epaulettetes and tabard
- Staff Nurse (Paed): - white uniform with blue epaulettetes and tabard
- Staff Nurse (Gen): - white uniform with blue epaulettetes and no tabard
- Care Assistant: - white uniform and tabard
- Student Nurse (Paed.): - pale pink tunic and navy trousers
- Student Nurse male: - white tunic with pink epaulettetes and navy trousers
- Student/Nurse (Gen.): - pale blue tunic and navy trousers
- Agency nurse: - usually white with no epaulettetes, or royal blue
- O.T.: - white top with green epaulettetes and green trousers
- Physio: - white top with navy epaulettetes and navy trousers
- Senior House Officer: - own clothes and white coat
- Registrar: - own clothes and sometimes a white coat
- Consultants: - own clothes.
An incomplete key was available in a booklet available for patients, although not routinely given out. My sense was that parents and children quickly decided on whom it was appropriate to ask certain questions and who it was not by trial and error.

4.2.5 My role as participant observer

I trained as a nurse in the mid 1980's and it was very strange for me to be walking on to the ward again after nine years of working as a nurse, but in settings other than the ward. The environment was strangely familiar, yet alien to me. I was struck by the way my feelings fluctuated from apprehension and unease at entering an institution which dealt with illness and death and a confidence that comes with a sense of being in the know of the "inner workings" of hospitals and of "things medical". These feelings did not subside as the pilot progressed, but rather got complicated by what I started to feel as a researcher in this environment. I noted after the second day on the ward a feeling almost of elation that I could now do the things that I had always wanted to do, as a nurse, but never had the time for. I thought I would enjoy talking to the staff, the parents and particularly playing and talking with the children.

On other days I felt disheartened. Few staff said 'hello' to me when I walked on to the ward (this seemed to be common practice to all visitors). Staff were very busy and the atmosphere on the ward was often "uptight" as described by SSN.Hel, one of the newer staff nurses. Like James (1984), I experienced contradictions in my role, I put my coat in the office, whereas the nurses put theirs in the linen room. I was on first name terms with the Manager of Children's services whereas the nurses were generally not. Yet I took no responsibility for patient care, and no doubt did not appear to be doing much. This led to a sense of confused identity, not just for me, but for the staff as well.

My approach was to try and get accepted by as many people as possible, starting with the nurses. My main ploy was to say and to demonstrate that I could be useful. I could make beds and help children with their activities and this in turn gave me the opportunity to do some research. I often started up conversations about dignity with nurses as I made a bed with them, or gave out lunches. Some of the nurses obviously felt suspicious about my role, as S.N.Jac. put it:
"You'll be watching the nurses won't you?"

I was very conscious of becoming party to confidential pieces of information about the children and their families. I felt uncertain about being told, or overhearing information that at one level was "none of my business" as I did not need this information to influence the care of the children or their families, yet gave useful insights into the workings of the ward and the care of the children. I felt a bit of a voyeur, feeding off bits of information that were not my concern and this was not very comfortable. Sometimes, no doubt because I was in a uniform and had a name badge, this confidential information was very freely passed to me, even personal comments about students, as I was known to be a trained member of staff.

My reactions to my role, the ward, the children, parents and staff was also coloured by my own experiences of a mother and my son, then aged two years five months. I found myself using my son and my experiences of bringing him up as a yardstick for what I saw. I was particularly aware of this when I was with Lester and Euan (see below). I would think back to what my son was doing at that age, and asking myself how I would react to my child being in this ward. My role as mother, however, was extremely useful in "breaking the ice" with parents and giving me a sense of what children of particular ages enjoy doing, of children's television programmes and, through the children of friends, what music and pastimes are popular with older children.

4.2.6 The Nurses

Before going on to describe my observations of the nursing staff, I have included the philosophy of care for the ward that is displayed on one wall of the parents' room.

X Healthcare Trust

Women and Children Care Group

"A Philosophy of Care for the Paediatric and Neonatal Nursing Team"

The nurses who care for the children and babies at this Hospital believe that:
1). Care in hospital shall be provided in a safe, secure and welcoming environment in which children and their families can receive the best possible quality of care.

2). Nursing staff shall promote positive attitudes to health and illness and will act as health educators at all times.

3). Each child and their family shall receive care that is sensitive to their individual physical, psychological, emotional, social, cultural and religious needs. Respect should be paid for the need for dignity and confidentiality.

4). Each family shall receive the care of a named nurse who will act at all times as a family advocate.

5). Children and their families will be encouraged to be involved in the planning and delivery of care. They will receive information, support and teaching that will help them to become ‘partners’ in care.

6). Whenever possible the care of children should be undertaken in the privacy and comfort of their own home.

The positioning of this notice made it easy to see for all the parents that used that room, but well away from the areas that the nurses worked in. I wondered how many of the nurses had read the philosophy, or even knew that it was there. I was interested to see that dignity was cited as something to be respected, but there was no guidance on how this should be done, or how one might know when this had been achieved.

In reality, the ward had adopted “team nursing” rather than a “named nurse” approach. This was because of the high numbers of temporary agency staff, high turnover of patients and high numbers of sisters who worked part-time. Moreover, there was a degree of task allocation on the ward, with Care Assistants “making up the feeds” for all of the babies on the ward and giving out the food at mealtimes.
I had intended that the first couple of days be spent mostly talking to the staff. I hoped that this would introduce me to as many people as possible and allay suspicions as quickly as possible. The fact that I had not yet received police clearance meant that this was a sensible option.

I had arranged my access to the ward through the manager of Children's Services and so when I rang to confirm my start date, I was disappointed that she was not going to be there on that day. She said that she would let the Ward Manager know that I was coming and would leave out a tabard for me to wear. When I arrived the Ward Manager passed me an envelope inside which I found the tabard. She was busy with another nurse at the time and so she told me to go and find Sr E. who was in charge of the ward that day. Sr E. greeted me enthusiastically, although she had not expected me. I was encouraged by her interest in my research and she had some interesting comments about dignity.

I was not always greeted warmly. Being busy often got in the way of both my introducing myself, talking about my research and saying goodbye. My notes from 1 May are an example of this:

I arrived on the ward at about 10.30 and introduced myself to a sister whom I had not met before. Yes she had heard that I was coming and thought that dignity was well worth researching, but she was very busy today.

Sr. Jan: “You'll see a lot of people under stress here today (I guess she probably means herself included)

Later, in the treatment room I ask her about dignity:

Sr Jan: “Dignity is very important – some people you'll find don't know what it is. I expect you'll find that said to you again and again...doctors especially. Not enough attention is paid to dying with dignity”

R: “What do you think dignity is about?
Sr Jan: “I'd love to have a conversation with you about dignity, but it will have to be another day…”

(Sr Jan smiled and walked away briskly).

When the nurses were busy they did not make eye contact, not with each other, not with me and nor with the parents and patients. In the mornings the sister in charge invariably
spent the shift poring over the notes trolley with the doctors as they did their ward rounds, making them unavailable to the rest of the ward. Nurses would walk quickly up the ward looking in front of them. I felt uncomfortable trying to attract their attention at times whilst standing in close proximity. I noticed this occurred when others tried to attract attention. A dietician used the technique of ostentatiously looking at name badges to get himself acknowledged.

Parents would hover at the doorways of their cubicles and try and gain the attention of the nurses. I reacted quite angrily to the inaccessibility of some of the nurses due to busyness, which no doubt was a frustration shared by the children and their parents. I recorded this in my log on my last day as:

*You can't hide behind your busyness forever!*

These words, written in haste, prompted me to think about whether nurses do hide behind their busyness? I speculated on the way nurses are always described as “busy” and wondered whether busyness was one of the few excuses that were sanctionable for nurses not to be attending to the physical and emotional needs of those around them at all times.

On my first day on the ward April 2, I made this observation, a very subjective one, about the demeanour of the nurses as compared to the Play Staff and Teachers:

*The nurses in comparison seem quite uptight and obviously busy, serious. Some are a bit hyper, others grumpy, others very pleasant and apparently "on top". I wonder what support they (the nurses) get, whether they have time for reflection. There is a huge turnover on the ward with a lot of agencies.*

The morale of the nurses seemed particularly low on the 5 May. At lunchtime I found CA.Jan. crying in the kitchen before the start of her shift. The ward clerk and CA.Wil were complaining about Annual Leave in the office, as were two sisters at the nurses’ station. The Manager of Children's Services called a meeting to which all were expected to attend. All except for the sisters, and I can only assume that they knew the news already, that the new building was not going ahead. I went along to the meeting, but I was asked to leave and feeling uncomfortable I left for the day. I recorded in my log:
I have a strong reminder of the sorts of things that led me to leave nursing on the ward.

The number of agency staff on the ward meant that it was difficult to maintain a sense of a coherent team. I noticed that there was very little, if any, banter or chat amongst the nurses as they went about their work, or even at report. When agency staff arrived at report, they were not acknowledged until the end when patients were allocated for the shift.

I asked CA.Jan whether they had a system of clinical supervision.

CA.Jan: "What's that?"

R: "Do you get opportunity to discuss what you feel about some of the children with someone?

CA.Jan: "When I was upset about this girl I told you about, I had a chat with a couple of the sisters and they were very supportive. Now and again we have a priest or someone - when a child dies"

I later discovered that plans for the introduction of clinical supervision for trained and non-trained staff were under-way.

I was conscious of a hierarchy on the ward, with one sister, Sr. X (April 21) referring to a student as "the student". When nurses answered the telephone they answered using their position rather than their name, almost as a way of not taking personal responsibility. The care assistants and most junior staff were expected to give out lunches for the whole ward, with the sisters sometimes making a special request for one of their patients. My position in the hierarchy was uncertain and fluctuating. I was told off on my first day by CA.K for giving a lunch to a three-year-old sister of a patient whom I had mistaken to be the patient. I felt guilty at making such a mistake on my first day, but then thought that I would have probably given her one anyway had I known she was a visitor as she had been sitting in a cubicle for most of the morning.

The nurses had very different styles in relating to patients, some like SSN.Hel were very softly spoken, and others like Sr X used humour to cajole the children. I wondered how
their manner reflected their attitudes to the children and the promotion of their dignity. Some of the nurses felt unable to condone the behaviour of their colleagues on occasion. CA Jan. talked about how she did not like it when nurses “talked over the children” and had been “appalled by the some of the nurses, and doctors had reacted to a 14 year old patient with special needs. Apparently they had shouted at her and shaken their fingers at her within close proximity when she had refused to do what they wanted her to do. “Some of them don’t like it when the children don’t do as they are told” This made me think of the very delicate position nurses have in the role of carer, protector and controller of the children while they are in hospital.

The nurses did not play with the children, except for the babies. This was left to the Play Staff.

4.2.7 The nurses of the Home Care Team

It seemed important that, during the course of the pilot study, I should talk to the members of the Home Care Team. This was a group of children’s nurses with a community qualification, and extensive experience, who visited the children in their own homes. The majority of the children from the wards were known to the team and seen either at home or in clinic. The Home Care Team therefore had a considerable impact on the overall care of the children.

My notes on the Home Care Team are based on one visit on 12 May 1999 and my discussion with the Acting Manager:

I found the office of the Home Care Team on Tulip Ward. Their room was a hive of activity, with nurses talking to one another about equipment, another on the phone and paperwork everywhere. There were several packets of biscuits open on the table, which I took as a good sign. HCT Cat had remembered I was coming and offered me a cup of tea. I had described my research on the phone to HCT Cat and I explained that I had come to find out about the service and to see what their thoughts were about dignity and the child.

The service was set up in 1989 to promote early discharge and to support children at home, both in the short term and in the long term. This was with the aim of promoting the child’s development within the family. There should have been six nurses in the team,
but they were down to four whole time equivalents. Increasingly their work was with those children with chronic and complex problems, for example those with leukaemias, tracheostomies, oxygen dependent babies, those from SCBU and those with feeding problems. Referrals came from the hospital, parents, family doctors and specialist hospitals. Procedures that were previously undertaken by the team such as removal of sutures were being referred to Practice nurses or back to A&E. Many of the children needed expensive equipment for them to stay at home. Respite care for the families was something that was not easily available.

At the time of our interview the team were seeing children aged between 0 – 16, or 19 where the child had special needs. The team was split into two, with each part covering half of the borough. Each nurse had her own caseload and also had a responsibility for a specialist clinic at the hospital, for example oxygen dependence, Cystic Fibrosis, diabetes, eczema and asthma.

I was struck by the very different atmosphere of the office of the Home Care Team and that of the ward, or even the staff room on Lloyd Ward. All the nurses in the Home Care Team had clinical supervision. I asked HCT.Cat whether she would go back to nursing on the ward, and she laughed “I wouldn’t go back to working on the ward!” (At this HCT.Cat asked if any of the others would and it is unanimous that they would not:

"We are extremely busy though (as if she needed to justify herself) but here is better continuity and you can make a difference. It is a shame to drag the child back to hospital if they can be seen at home"

After discussing the service itself we moved on to dignity, my notes from our discussion are interspersed throughout the text

4.2.8 The parents

Both the Report of the Platt Committee (1959) and the Report of the Court Committee (1976) promoted the involvement of parents putting greater emphasis on family centred care. One of the principles underlying these recommendations is described by the Audit Commission (1993, p.9) as:
"Children are part of a family and are dependent on their parents for physical and emotional care and support. Caring for a child means involving parents and siblings."

Despite this, parents seemed to have quite a low profile on the wards. Several seemed to spend their time hovering in the doorways of their cubicles. Where children were in one of the open bay areas, parents could put up camp beds next to their children. The beds were very close together and the ward seemed very overcrowded, with the parents almost touching one another. A “Parents’ Room” was equipped with a microwave, kettle, pay phone and some low chairs. A toilet and shower room led off from this. Parents could get food from the staff and visitors’ canteen on the ground floor, or they could bring in their own food to prepare.

S.N. Mart commented on the lack of privacy parents had all sleeping next to one another. S.N. Mart worked just one day a week and her experience with one of her own children being admitted to Lloyd Ward had made her sensitive to the plight of the parents. The dignity of the parents in these conditions seemed hard to promote, all living in such close proximity, at a time of stress and concern for their children and all being open to the scrutiny of other parents and staff. Issues of lack of control and witnessing associated with the experience of dignity, seemed very pertinent.

CA. Jan commented on how the parents constantly watched other parents. She described a situation where a toddler could be having a tantrum:

“The parents are very much watched by other parents to see how they will deal with it. I think that makes the parents much tougher on them (the children).”

Some of the parents indeed seemed to express concern about how they may be judged by staff. An eight-week-old boy had been admitted from the fast referral clinic attached to Accident and Emergency. His birth weight was 7lb 6oz and he had put on very little weight since. The mother had two other children. She told me that her child would eat but then “bring it all back”. “Now he’s naughty and not doing it - people will think I am making it up.”
Nurses seemed conscious of the role parents had in giving consent and advocating for their children. A student nurse, on his first ward, posed the dilemma of parents not wanting a male nurse to care for their child and having to concede to their wishes. I asked him how he would react if the child really took to him, and opened up to him in a way that they could not do with other nurses.

St. N. (Paed) 1. "You’d have to go with what the parents wanted".

He did not go on to continue a discussion about the dilemma he might feel, nor question the dignity and the rights of the child, nor its age, or other strategies.

Another example of managing conflicting wishes of parent and child occurred when I was speaking to a staff nurse on Lloyd Ward. She recounted an incident where a child had been running around the ward with no clothes on. One of the nurses had put a pair of pants on the child and the father objected. I asked how old the child was, and she replied that he was about four. Another nurse removed the pants and the child was allowed to continue as before. The nurse asserted that this was in keeping with the child’s dignity and choice.

I was unconvinced that they were taking into account what the child wanted, but rather what the father advocated for. This brings to mind the role that nurses have in the care and control of children and the wider role adults have in promoting social norms as part of the child’s social education. It also provokes the idea of the protection and promotion of dignity of the onlookers on the ward who may be offended and made to feel uncomfortable.

4.2.9 The children

The intake on to the children's wards reflected the diversity of the community served by Hospital X. The two children's wards took children up to the age of fourteen, with the older children going to adult wards. I was told by one of the teaching staff that when a thirteen year old was admitted from Accident and Emergency, whether they are taken on to a children's ward was arbitrary. She explained: "if they are big they go to an adult
ward" (T.M.) If they needed intensive care they would go to the Intensive Care Unit which was an adult unit.

When the ward was very busy, as it was on 1 May, I noticed that the babies got left for longer periods in their cubicles and there was more crying. On 1 May the parents of three of the babies were not on the ward. I found myself going from one to another trying to comfort them. I soon became accompanied by Olaf (8), and Mohammed (9), who followed me from cubicle to cubicle. I was touched by their concern for the babies crying and they would try different musicals and toys in an attempt to pacify their fellow patients.

CA.Kat, loudly referred to Olaf, on his admission, as "the infected eczema". He was able to care for himself for much of the time except when he underwent his complicated bathing and dressing rituals. He got constant reminders from the staff as they went past to stop scratching. Olaf was covered with eczema from his face and head, down his trunk to his legs.

“Your nose is really handsome you know,” said CA.Wil as she passed by his bed. Olaf’s nose was apparently the only bit of him that was not infected. Olaf did not seem to want to talk about his eczema. When I asked him if his back was the itchiest part, he clammed up and would not speak.

The food arrived each day from the kitchen in a big truck in the shape of Thomas the Tank Engine. It was transferred on to a trolley and taken down the ward by the staff. There was no choice unless the children were on special diets that had been pre-ordered. Generally the food looked pretty unappetising. I was surprised how little the children complained and yet, on reflection, the children were probably used to having food put down in front of them with little choice. They may even have been more choice in hospital. They were usually given meat, casserole or pies, always mash, often with carrots or mixed vegetables. There was often a crumble for pudding with custard, which was generally more popular. The halal food was always spicy and not always suitable for the children, Olaf complained that the hotness made his eczema more itchy. The children were encouraged to eat on one of the central tables out in the bays, although they rarely did.
Choice and control seemed limited for the children. Giving credence to the child and their wishes today is a difficult task for all those who care for children. Those who care for children who are ill have a difficult role to play. H.C.Sr.K commented that:

"It is difficult when the child may not want treatment, but the adults all want it. It is especially difficult in adolescence when they are trying to establish their own identity."

I asked her how she dealt with situations like that.

"We have different strategies - we explain the treatment again as it may be that they just don't understand, you try to be on their level - get to know them"

4.2.10 Dignity

As I introduced myself to people on the ward, I frequently used my research topic to find out what they thought dignity was and how and if dignity was important to children. One of the most common responses was to equate dignity with privacy. A typical response came from CA.K.

"Dignity – well it's the same for everybody isn't it. It's about privacy, about pulling screens around and covering people up."

Similarly Sr.X. responded:

"Dignity – well its about privacy and confidentiality"

And Sr. Scar:

"Well, its about privacy isn't it. I mean drawing the curtains. Not for all children, I mean toddlers, we wouldn't always draw the screens to change a nappy."

S.N. Jac is a permanent member of staff on the ward. She gave a similar definition of dignity:
"It's about keeping the curtains drawn isn't it and that kind of thing."

I was struck by the way some of the nurses did not give their definition of dignity, but rather went on to operationalise it. I wondered whether this was a learned response of nurses, a habit from working on a busy ward. I wonder what this says about the nurses' opportunities for reflection. I wondered too about the purpose of screens and the question of whose dignity the nurses were aiming to protect, the patient or the wider ward population.

I had noticed that the screens were invariably pulled across the cubicles which were frequently used for children who were neutropaenic following chemotherapy. On May 5th, I noted in my log, "sad eyes peering from behind the screens of their cubicle" and I wondered if one could be too quick in isolating such children further by pulling screens across their only contact with the outside world.

The action of pulling curtains around in the midst of a busy ward, it could be argued, is merely a symbolic preservation of privacy. One may not be able to see through curtains but they provide little containment of smell or talk. Indeed the very act of drawing curtains can act as a prompt, as if to say 'something confidential is about to happen behind these screens' I wondered what the role of screens had in keeping the occupant 'safe' with their dignity intact and what role they played in keeping the potential spectator safe from the sights behind the curtains, and their dignity preserved.

Sr.M. commented on the use of screens:

"Curtains and cubicles give a sense of privacy – there is the difficulty of discussing the patient inside the cubicle or outside on the corridor"

Her comments also made me think about the issue of control and the awareness of discussions taking place outside in the corridor to which the patient is not party, and yet any passer by is.

Some of the nurses gave different definitions of dignity. C.A.Jan works 28 hours per week and said
"Well dignity is very important. It is about allowing children space. Not exerting control over them, but allowing them some choices and autonomy."

I was curious to know whether the nurses thought that dignity was different for children as opposed to adults, and if so what ages were important.

Sr.M: "Dignity is the same as with adults, or more important, as they may not know about it."

Comments such as these lead me to question again whether adults who care for children had a role to play in the promulgation of social norms and the relationship of social norms and dignity. How is dignity socially constructed?

C.A.Jan. was careful not to make a distinction between the way one might care for an adult and how one may treat a child.

CA.Jan. "You're not sure what they understand...even when changing nappies you want to be respectful don't you?"

On my second day on the ward I asked the ward clerk what she thought about the concept of dignity

WC. "Is dignity different between children and adults? – yes it must be different as they develop a sense of themselves. It's about respect."

Later that day I introduced myself to a staff nurse doing long-term agency work. She was from Kuching in Malaysia.

S.N.Mai: "They develop a sense of dignity at their age of consciousness."

R. "What sort of age do you think?"

S.N.Mai: At about five years – they get embarrassed by things. They won't get undressed. It depends on the background of the child."

On April 29, I had a similar conversation with Sr Scar:

R: "What age do you think children become more aware...?"

Sr.Scar: "...and get embarrassed? – well obviously teenagers."
P: “And before then? Is there a transition between babyhood and child?”

Sr Scar: “Yes, say three, they become more aware.”

I asked a sister from the Home Care Team:

R. “Is there a difference in the dignity of a child and an adult?”

HCTCat: “Well people say ‘they are only a child’, but here is no difference. You need to be familiar with child language to be able to communicate with them.”

R: “What about babies, how do you promote their dignity?”

HCTCat: “Well, you behave in a way that demonstrates you are respectful to the child. You involve the parents, you don’t want to take their child away – empower parents by getting them involved in the care.”

A student nurse interpreted my question rather differently

St.N.2: “Dignity is difficult to define. It is about respect and rights, these should be no different from conception to death.”

I was not sure from her answer whether she was referring to a foetus. I asked her how she might demonstrate respect to a child:

St.N.2: “You explain procedures and talk to them.”

Her experience prior to entering her nurse training had been working with people with dementia, which, I commented would have been an area where dignity was important. Our discussion led to the idea of death with dignity and I asked her what she thought the promotion of dignity meant.

St.N.2: “Not to be ignored, but to be recognised as an individual and treated with tender loving care.”

A more individual approach may be easier to promote in the home environment. The sister from the Home Care Team commented:
HCT.Cat: "At home it can easier for the child to have their own say — 'I just want Mum here' for example. Of course we only ever expose what we need to for any procedures. In hospital children are often confined to their cubicles that is not the same at home. But even in hospital the child and the family come first."

She went on to say that dignity is a very important part of care, both in the clinic and in the home and;

"When visiting children in the community, you must always remember that you are guests in their home. Wherever you see the child you look at what is in the child's best interests and the family's. You must preserve their privacy and take note of whom they want present when you come to visit them.

One sister commented on the difficulty of distinguishing the child from the adults in the family. When explained what my research was about she asked:

Sr.M. "Do you mean the dignity of the child, or dignity of the child and the family?
R: "Both" (I replied as I was aware that they could be conflicting).
Sr.M. "You have to be very careful — what you might divulge about the family of a child. You have to choose what is important and not use the information loosely."

The nurses gave definitions of dignity, ranging from internal definitions to practical approaches. There was no consensus over the age they thought dignity became an issue for the child themselves. I did feel somewhat disappointed in the uniformity and the simplicity of the responses given by the nurses when asked what they thought dignity was and the way dignity was equated with privacy. Of course the responses nurses gave whilst on duty and with other things on their minds might be very different to what they would say if they were interviewed away from the ward setting. Whilst on the ward the nurses reflected upon how they "did" dignity as nurses rather than what dignity meant. This could be addressed by modifying the design of the main study, for example interviewing the nurses away from the ward when they were not on duty. Although my original questions about dignity concerned the dignity of the children, I became aware of the way the dignity of the parents and the nurses are intertwined. This will be explored further in the main study.
4.2.11 Teachers and play staff.

When I introduced myself to P.S.Kat, a play worker, I was felt reassured when she told me that the teachers and play staff had heard that I was coming and that their "Head" had circulated the information that I had sent.

The teachers saw all school age children admitted to the hospital, that was those aged between four and sixteen and some of the nursery aged children. School materials were available for children aged four and above. Most of the children are admitted to the two children's wards, but the staff saw children throughout the hospital. They found out who had been admitted through the Chaplains' List, which detailed all admissions. The teachers also saw children in their homes who are unable to attend school for medical reasons. T.E. reported seeing a number of children with Myalgic Encephalopathy.

The play staff concentrated on the younger children and babies and, together with the teachers, they seemed to make up a cohesive team. The turnover of staff was not as high as for the nurses. T.E. said that they maintained good relations with the nurses and one of their team attended the midday handover every day. According to T.E. their need for support was well recognized and, as well as one another to rely upon, they were able to get more formal support from the staff on the continuing care unit.

I arranged to spend one day, May 6, with the play and teaching staff so, rather than going on to Beauchamp Ward, I went straight to the teachers' base at the far end of Lloyd Ward. I was met by T.J. and T.E. both teachers. The play staff were already on the wards with the other children. Two children were in the classroom, Billie aged ten, and Dipak aged eight. They were playing with puzzles, such as codes, and on the computers. While the children were busy, I asked T.J. about dignity.

T.J: "It's about remembering the child as a whole person, not 'it' with no talking as if they weren't there."

Billie seemed quite happy to be in the classroom. She had been quite withdrawn on the ward, but was laughing and talking with the teachers. Dipak seemed less happy, and although he proceeded through his tasks, he was very quiet. He asked to go to the toilet
at one point and walked back to the ward and did not come back until T.J. went to persuade him.

I spoke to T.E. for some time about the structure of the teaching staff, their training and the aims of the service. The latter I have set out below:

- Familiarising: for short admissions with hospital procedures, the different staff members etc.
- Normalising and continuity of education. If children are going to be in hospital for longer than a week, the school is contacted and work sent in for them.
- Self-expression.

I was interested particularly by this third aim as the teaching and play staff seemed to provide one of the few opportunities for self-expression on the ward. Children were able to respond and behave differently from when they were on the ward. I was interested and encouraged by the way this contrasting environment could offer me a "natural" opportunity to interact with the children and undertake some research in this setting.

4.2.12 Favourites

I became aware of a "ward favourite" on my first day as I was accompanying PSKat, one of the play leaders around the ward.

PS.Kat. “Lester is our favourite”

She went on to explain that Lester was one of twins, born 15 months previously at 24 weeks. His mother had since died of cancer. The other twin and a three-year-old sister lived at home with the father, but Lester had never been home. I asked if she knew what the long term plan for Lester was?

PS.Kat. “Well, he is oxygen dependent, which means he will be difficult to manage in the home. We (I think she means the Play Staff) do as much as we can with him.”
I was struck by how different his life had been compared to children brought up with their family in a home environment. He lived in a cubicle opposite from the nurses’ station. He was not quite sitting up, so most of the time he was confined to his cot attached, via nasal cannulae, to his oxygen. There was a television in his room that was left on for most of the time and he was left for long periods particularly at weekends when no Play Staff were on duty, or when the ward was hectic. The play staff took him out in his buggy, as did the nurses if they had the time. If he refused his food, he was fed via a nasogastric tube. He stayed in his room to be fed. Lester was generally quiet and undemanding. I found myself wondering about his opportunities to make friends with other children, to have new experiences and to form close bonds. No member of the family visited Lester when I was on the ward. I later learned that there was a plan to discharge Lester home in June.

As well as feeling concerned about Lester’s individual circumstances, I also felt uncomfortable with the notion of favourites, and being the ‘pet of the ward’. I wondered if this meant that there were non-favourites and questioned how this might affect their care.

On 5 May I noted my surprise at seeing St.N. Gen. “just sitting and cuddling Anne Marie”. Before then I had only seen her being cuddled when fed. Anne Marie was suspected of having a chromosomal abnormality. I had previously been talking to S/N Malay when she said “listen to that cry, its not normal is it?”. Anne Marie’s mother worked elsewhere in the hospital; she was assertive with staff and was one of the few parents I saw stopping doctors on the wards and asking them questions directly. Anne Marie looked slightly different and she responded differently from other babies, she tended not to snuggle in when held, but threw her head back. I sensed Anne Marie, and the family, were not favourites. It seemed that the suspicion over her normality set her apart from the other children and the way nurses responded to her. St.N. Gen was the only one I saw to cuddle Anne Marie in this way.

Some of the nurses were quite stern in the way they dealt with the children. Those who were in for routine, short stays were not always treated sympathetically. Omar had been admitted on his sixth birthday to have his tonsils out. On his first day post operatively he
was crying in the corridor with his mother, complaining of pain. One of the sisters was shouting “Come on, don’t you want to go home” in the middle of this busy thoroughfare.

I voiced my concern about favourites to a Senior Lecturer in Child Health at the associated university. We speculated about the factors that make a child a “favourite”. They were long stay, parents rarely there, and also what the child is like and the affecting condition.

4.2.13 Doctors

Following my interview with the Local Regional Ethics Committee (LREC), I was advised to get in touch with one of the paediatric consultants who sat on the committee. Despite leaving three messages with the secretary over the course of the pilot, I did not manage to meet with any of the consultants. Nor did I have the opportunity to speak to any of the doctors about the research. This had to be rectified for the main study.

My field notes were sparse about the doctors. One entry concerned the treatment of a 12-month-old boy with “special needs” who was described by the registrar as “fairly unresponsive”. One of the consultants had instructed this doctor to obtain the permission of the mother for a suprapubic catheter specimen of urine to be taken from the child. This would have involved the insertion of a small tube through the lower abdomen straight into the bladder. The mother had refused, Sr.M. described the procedure a “very invasive” and supported the mother’s decision to refuse. She suggested that the doctor call the consultant at home (it was the weekend) and explain and try to reach a compromise. The junior doctor was obviously reluctant to interrupt his consultant, but nevertheless went ahead with the prompting of the nurse. The child did not have a suprapubic specimen taken that day.

4.2.14 Conclusions

By reviewing below the original aims and objectives of the pilot study, I will demonstrate how these influenced the direction and methodology of the main study.
The pilot study demonstrated the feasibility of undertaking the main study in a hospital children's ward, using an ethnographic approach. A number of amendments to the main study seemed appropriate and I have identified these below.

A longer and more intensive period of preparation prior to starting the fieldwork was required, including meeting all the members of the team; nursing staff, managerial and medical personnel and publicising my research more widely. This will ensure that as many staff as possible know of my existence and project before the official start date.

My experience of trying to take adequate field notes has led me to conclude that a tape recorder, in addition to my notebook, is necessary.

The larger data sets involved in the main study may preclude a manual coding and sorting of data and I should investigate using specialist ethnography computer software.

Following the pilot study, my intention had been to limit the age range of the children studied, for example 3 to 11 year olds. However, during the course of the pilot, I became aware of some of the issues concerning the 0-3 year olds, in particular the question of when the concept of dignity is important. I therefore decided to include this age group in the study. I recognize that the opportunity for being able to interpret their behaviours will be more limited and this will mean having to identify, observe and talking with the key adults.

Interviews with the staff during the pilot study were undertaken "on the hoof" For the main study it is more appropriate to interview staff away from the ward. Audio taping these interviews and later transcribing them will allow me to collect rich data from all participants.

The pilot study revealed the rich potential offered by the play and teaching staff in gaining access to the children in a setting that promotes self-expression. However, due to the delay in getting police clearance I was unable to assess the potential of using different methods to interview young children. I hoped that, in the Main Study I would have greater opportunity to use a variety of tools and techniques to facilitate interviews and ascertain the thoughts and feelings of the children. Techniques could include draw
and write (Mobley et al, 1996) puppets (Verscheren, et al. 1996), and storyboards. Images and equipment in the ward setting could also be used to stimulate discussion.

The pilot study gave me confidence in approaching both children and parents and talking to them about my research in an informal way. I will need to introduce myself at the earliest feasible opportunity to parents and the children if they are to be made aware of why I am on the ward. I anticipate two levels of observation: 'non-consensual', when I am on the ward and observing generally and 'consensual' when individual children and their parents give their consent or the child to be included in my study.

4.2.15 Further themes

The main aim of this pilot was to prepare for the Main Study. However, during the course of the pilot study and subsequent reading, a number of themes developed that I thought warranted further investigation:

- The symbolism of screens and cubicles in promoting privacy (dignity).
- The question of whose dignity should be promoted and the potential conflict of the dignity of the individual versus the ward population.
- The dignity of the nurses, doctors and families alongside the dignity of the children.
- The role the adults (especially the nurses and parents) have in promoting the social norms of dignity.
- Dignity as a social construction compared with notion of dignity as inherently individual.
- The protective busyness of nurses.
- The experience of time and its effect on the experience of dignity from the perspective of the child, the medics, the nurses and the parents.
- Favourites and favouritism among child patients
- The ward environment and its role in promoting different emotional climates and how this affects the child and their dignity.

4.3 Additional Pilot Work
The main aim of undertaking additional pilot work was to observe children in alternative institutional settings to the acute hospital. I was interested to see how children were conceptualized in a different organizational culture and how meanings of dignity might differ.

4.3.1 The Children's Hospice

I wanted to collect comparative data from additional environments to explore how environment and culture affected the meaning of dignity for children, their families and those who worked with them. I was drawn to researching children and their families in the setting of a Children's Hospice. In adult hospices, patients are generally admitted for end of life care with increasing day and outreach care becoming more common. In contrast, children's hospices care predominantly for children and young people, with rare degenerative metabolic and genetic conditions, and their families. Care and support is offered to these families often over a number of years. Children and their families attend for respite, palliative and end of life care. I was particularly interested in the way children whose future's were acknowledged to be limited, were cared for. Despite visiting the hospice, meeting with the senior staff and twice submitting a proposal for research, my application and revised protocol (Appendix 6) was declined on the basis of needing to protect the children and their families from unnecessary intrusion in a designated safe place. I appreciated the time and thought spent on my behalf and on my research. I was able to visit, examine their philosophy of care and talk with senior staff in order to obtain some sense of the organization, their ethos and work they undertake.

This experience helped me to consider the way children, and sometimes the very same children, are constructed from a different perspective. The service was set up for life limited children who are expected to die before they reach nineteen. The hospice provided important respite for families caring for the sick children, a change of scene and the provision of a range of recreational and therapeutic facilities and support at end of life. The families receive respite from caring, respite from being a burdened and, sometimes stigmatized, family; respite from a nosey world.

The staff, both salaried and voluntary, seemed to share a mission. The children were constructed as different and special. Because of this special status they attracted free
tickets to concerts and film premiers. The hospice provided a haven for Life Limited children and as such attracted goodwill and charity. The hospice was supported as a special place where these children can be cared for away from public life. I had a sense that the hospice was the icing on the cake, that covers over and detracts from the cracks and deficits in mainstream service provision for children. I detailed the mission and the values of the hospital of the main study in a previous section, and by comparison to the hospice, the mission seemed to be difficult to hang on to at times. However, the same life limited children had to go into hospital at times and their needs were addressed very differently.

At the hospice non-medical family orientated language is used on the care plans for family and staff to fill in. For example one section asks what are the indicators of the child becoming unwell. Illness is not defined by medical measurement, but as a more subjective measure and the power is left with the parent and child. Diagnosis is not a priority, indeed some of the families have children "with no diagnosis" but nevertheless parents have to deal with the knowledge "your child is dying, but we don't know why".

The specialness of the children appeared to bring the families together in a sort of camaraderie. The staff and families eat together in a communal dining room. The building is on one level apart from the family flats above. The child's name is put on the room where he or she is expected, as well as at the front door.

The uncertainty about the end of life remained as 'is it now or another time?' But there is an acknowledgement that the premature end of life is inevitable and energy goes into making the last few years and months and days as good as possible. The ethos is not future oriented and spirituality was overtly addressed. Nevertheless, the end is always a shock and sometimes staff more ahead of family in what will happen next and the staff have to moderate their approach to the families accordingly. It was striking that the hospice attracted huge amounts of charity and goodwill from the general public. Sontag (1991) discusses the use of metaphor for unthinkable, mysterious diseases such as cancer. The hospice, I suggest, has become a metaphor for managing and controlling the unthinkable, that of a child dying prematurely.
At the hospice the subjective experience of the child and family was acknowledged rather than medicalised. The emphasis for the provision of care was the here and now. My time spent at the hospice highlighted the way children and their families were constructed on the ward by offering a contrasting perspective.

4.3.2 Observation at a school

I considered exploring the notion and meaning of children and dignity in the setting of a school. I spent the period of one term listening to Year One (5-6 year olds) children read in a primary school for one period a week and, on one occasion, accompanying them on a school trip. In doing this I was able to observe children in a contrasting institutional setting, without their parents.

It was revealing how children were very ready to formulate their own interpretations of what they saw and experienced around them. An example of this was when the vicar asked the pupils what they thought the wonderful gold coloured bowl on a lecturn was for. There followed a range of explanations from the children, including a “rubbish bin”. This remark was not well received as, the vicar explained the receptacle was the new font for baptizing children.

The children moved constantly and rather than being constrained in their bodies in the way the sick children were, they were liberated. The children in the school seemed freer to participate in events around them and to establish their own friendships independent of parents, though overseen by teachers. The school, however, did not attract my research imagination as an arena to investigate dignity in the same way as the hospital (4.4).

4.3.3 Observation at a nursery

I was interested to observe younger children in their daily lives and watch how they behaved and interacted. Pilot work at the nursery was limited to three days spent with the top, Pre-school class (3-4 year olds). During this time I experimented with non-participant observation. I was introduced at the beginning of each day by the class supervisor. I remained seated and took notes on the children’s activities and behaviours.
Adopting a non-participant role, quickly seemed very unnatural. The children would approach me and want to know what I was doing, or writing. They wanted to know what I was there for and if I had any children. They wanted me to help them with buttons and picking things up. They tried to provoke me by behaving badly when the supervisor was not watching them and they touched me and wanted to sit very close by or on me! Once again, in comparison to behaviour on a ward I was struck by the constant movement and interrelating of children with one another.

4.4 Concluding remarks to the pilot work.

I undertook the additional Pilot Work primarily as preparation for the main study. My use of varying contexts, such as the school and nursery, enabled me to witness children in other aspects of their normal lives. In each setting the child, and children were conceived and constructed as something different. In the hospital setting, they were more passive and inactive, both physically and personally. They were separated out from their peers, as a result of their illness and the structure and organization of the ward. By seeing children en masse in the school and nursery, I was, very vividly, able to see the children as active and involved in these alternative settings. These insights into children in other settings throws into contrast the 'strangeness' of hospitals and, I argue the inherent threat to the dignity of the child. My experiences of being a nurse and part of a culture that seemed now so alien to me and to the children it served was important in my ultimate choice of the hospital setting for the main study. My commitment to researching the dignity of ill children in hospital was confirmed for me.

4.4.1 Reviewing the aims and objectives of the study.

Following the pilot work it was important to revisit my original aims and objectives of the research. The methodology using grounded ethnography and grounded theory was feasible and appropriate. Continued reading of methodology texts (Cutliffe, 2005; Charmaz, 2006) helped develop my appreciation of interpretive theory development based upon understanding of the phenomenon studies: dignity and the child in hospital. Such an interpretive stance is compatible with symbolic interactionism (Goffman, 1963, 1971; Benzies & Allen, 2001). My decision not to limit participants to
those aged between 3-11 years was the recognition of issues of dignity before and following these ages. It was also a positive choice to include all those defined as children by their admission to the ward and their families and embracing the total environment of the ward as my research theatre. In progressing my research to the Main Study, I was able to build on some of the indicators, constructs, and key concepts as they started to emerge from the pilot work. I was cautious not to evolve data too rapidly in the early pilot work, nevertheless early analysis suggested useful indicators and emerging constructs (Fig. 8).

<table>
<thead>
<tr>
<th>Indicators included:</th>
<th>favourites, busyness, individual versus the dignity of other(s), emotional climate, environment, time, role of parents, curtains, privacy, dignity changes as children grow up.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emerging constructs:</td>
<td>strangeness, macro and micro references to dignity, symbolism of dignity, the body, control, witnesses, construction of children</td>
</tr>
</tbody>
</table>

*Figure 8: Early indicators and constructs from the pilot work.*

Having described the issues that arose from the pilot work I will now go on to describe my Findings from the Main Study. It will become evident how themes grounded in the earlier work, described above, evolved. Committed to keeping a flexible and essentially inductive approach to the study I reviewed my initial aims and objectives to establish broad aims for the Main Study:

- Explore and further the understanding of dignity and the child in hospital.
- To evolve or dismiss early indicators and the emergent constructs of the pilot work
- To pay attention to the context and the subjective meanings of the participants.
- To identify further themes through progressive analysis concurrent to the data collection.
• Through successive levels of abstraction develop a theoretical explanation or framework in order to clarify the concept of dignity and the child in a way that is meaningful to children and for those who care for them.
• To undertake the research in a non-exploitative, person-centred way.
• To make recommendations for practice such that dignity can best be protected and promoted for children in hospital.

4.5 Codes for participants in the Main Study

Following the pilot work I adopted a way of coding participants quickly and easily at the first point of entry into the study. I have used these codes throughout the presentation of my Findings. I have coded participants in such a way as to allow me to include information about them. My choice of what criteria I needed to code was determined by my experience of the pilot work and the restrictions placed upon me in denying access to the medical records of the patients.

4.5.1 Codes for staff participants

In order to identify staff, I allocated codes in the following way:

The first number, for example “1” indicates the order in which I interviewed the participant.

M = male staff member       F = female staff member
N = registered nurse        D = doctor
HCA = health care assistant  StN = student nurse

Therefore 16FD represents the sixteenth staff participant interviewed, who was a female doctor. I have recorded further information on the Staff Data Sheet (Appendix 7).

4.5.2 Codes for children and their parents

In order to identify children and parent participants, I allocated codes in the following way:

M = MOTHER       F = Father       Ca = carer
C = child
M = male child    F = female child
8 = 8 year old 15.12 = fifteen month old child 6.52 = 6 week old child
080 = the eightieth child/parent identified in observation

Therefore mcm8080 would translate as the mother of an eight year old boy, my 80ᵗʰ child recorded. These codes can be cross-referenced with the Child Data Sheet (Appendix 8) that gives more, albeit limited, information regarding their admission. These details were not sought from medical records or from the staff as my access was denied, instead this information was added to on discovery. Where I have included verbatim extracts from transcripts, “R” refers to me as the researcher.
Chapter Five: Findings from the Main Study

The voice of the researcher

5.1 Introduction

I have presented my Findings in three chapters representing the voices of the participants. Chapter Five describes my own voice in the form of reflections upon my field-notes. Chapter Six represents the voices of the staff and Chapter Seven the voices of the children and their parents. Throughout the findings chapters I have included quotes from the verbatim transcripts and situated the voices of the participants within the analysis. This also increases the transparency of my approach to theory generation. I have broken down each of the findings chapters further into the themes and sub themes drawn from the data. These themes correspond across interview data sources, allowing for easy comparisons.

The first of these chapters records my own voice as researcher. Originally I kept all my observation findings separate from the findings from the interview data, but this seemed a false and unhelpful division. Although, this separation was useful at the beginning of the data collection for organizational reasons, it later served to dilute and decontextualise the data. Moreover, the links between observation, what participants said and my interpretations could not be demonstrated. I have therefore integrated my observations into the findings from the children/parents and the staff interviews. Only where observations have direct relevance to the environment or my role as researcher, have I included them as data in this separate chapter recording "my voice."

It is the very nature of qualitative research methodologies, such as ethnography and grounded theory, that the researcher is part of the data and my 'self' is represented in the findings. This is in an attempt to:

- set the scene from both a physical perspective and my own emotional reaction (5.2).
- understand the experience of the research for myself as researcher. (King, 1996) (5.3)
- make explicit my self as researcher and my part in co-constructing the data with participants (5.4).
5.2 Setting the scene.

In this section I will first describe the hospital environment in which I undertook the research. In so doing I illustrate how factors such as the environment and my experience on the ward informed and was influenced by my methodology. I will also make apparent the context in which the observations and interviews were undertaken at the physical level of the environment and at the personal level of the researcher.

I should note here that I have used the term ‘child’ or ‘children’ throughout, rather than using ‘young people’ when referring to those aged over 12 years of age. This is a reflection of the way children were referred to in the research site, that of the “Children’s Ward” and in keeping with the apparent homogeneity of provision for all ages.

5.2.1 The ward environment

The hospital chosen for the Main Study was a medium sized District General Hospital with 520 beds, treating 260,000 patients per year. On entering the hospital, a sign with the “Mission and Values” of the hospital greeted me. The second stated value was “We treat everyone with respect and dignity”.

There was one ward in the hospital devoted to children. This was a general paediatric ward treating children and adolescents with a wide range of conditions and including the specialist treatment of oncology, ear, nose and throat, ophthalmology, maxillo-facial and orthopaedics as well as general medicine. Within the ward there was a designated bay for ambulatory care. In a separate part of the hospital, there was a designated Out Patients. When children attended the Accident and Emergency Department, they were seen in a separate area during daytime. Children used the Day Care Surgery Unit and other departments in the hospital such as radiology, orthopaedics and ophthalmology, as well as the main theatres.

I commenced the main stage of the fieldwork three months after the “new” ward opened to replace one that required substantial updating. It had been designed following focus groups of parents and talking to the children. Staff undertaking this research had sought to include the needs of children of different ages and including special needs children,
babies and parents alike (12FN). Nevertheless there had been financial restraints on the development of this “new” facility.

The physical structure of the hospital and ward influenced how children moved around the space available. The way they behaved and were able to interact with others, staff or patients, was also affected. I argue that this in turn had considerable repercussions for the way children were treated and cared for and played an important and powerful role in the promotion and maintenance of the dignity of children.

I have sought to include, under the heading of environment, not just the physical layout of the ward, but also the noise the smell and “the vibe”, a term provided for me by one of the Health Care Assistants on the ward, 3FHCA. I took “the vibe” to include the emotional atmosphere of the ward. Attention to these factors enabled me to get an idea of the ‘total environment’ experienced by the children their parents and the staff. The environment of the ward was important as a backdrop to events taking place on the ward, in defining the physical world of the children and confining their bodies and the bodies of their parents and staff. The layout of the ward was important in determining the movement of the inhabitants.

Menzies Lyth in her study of the psychological welfare of children making long stays in hospital, notes the differences in both physical and psychosocial terms between the home and hospital environment (Menzies Lyth, 1982). She explores the importance of what she terms boundary control. She describes the home as a “bounded place” where the outside doors form a physical barrier to those without automatic rights of entry such as family members.

The ward in this study was sectioned into bays of up to six beds and side-rooms, thereby creating smaller bounded spaces (figure 9, overleaf). These in turn opened out on to a corridor. The corridor had a steady flow of people including cleaners, doctors, nurses, patients, parents and siblings. This corridor at one end was closed other than as a Fire Exit. The other end opened on to a large landing with lifts and stairs, marking the principle exit out and entry point into the children’s ward, and to and from the main hospital.
Figure 9: Diagram to show the layout of the Children's Ward
Access to the ward was via an entry phone or key-pad for those who knew the code and had been granted automatic rights of entry. The familiarity of the environment to some, contrasting with its strangeness to others of the environment, exacerbated the power differentials that lay between staff and new patient. The new patients and family needed to request permission to enter and in turn a sense of dependency was instilled. This was my experience too as I had not been given the access code prior to commencing fieldwork. The patient is increasingly conceptualized as a consumer of medical care, better informed and increasingly willing to challenge a doctor’s authority (Lupton, 1996). However, this means of controlling entry was also symbolic of a wider power imbalance that I argue persisted between staff and patients and their families. Responses to such physical controls mirror the dependence and anxiety integral to the medical encounter itself (Lupton, 1996). Passing through the entry point of the ward signified the entry into a domain controlled by others and associated with three particular areas of loss of control identified by Taylor (1979): loss of bodily control, loss of typical activities and loss of ability to predict what will happen.

My experience as the “new researcher” on the ward, I suggest, gave me some insight into the experience of the children and their parents visiting for the first time. At first, I felt constrained in where I was ‘allowed to go’, being neither parent nor staff and uncertain which areas of the ward I was able to inhabit. For this reason, in the first weeks of the fieldwork, I limited my use of the ward space. For example, for the first three months of the research I did not go into the office on the ward. This also increased my sense of likeness with the parents, rather than aligning myself to the staff. Later, in the fieldwork, I started to go into the office to check the names of patients on the board before approaching them.

5.2.2 Layout of the ward.

The corridor of the children’s ward was an L-shape with single rooms, small units and bays of six beds opening from the right hand side of the corridor. On the left were mainly the staff areas such as treatment rooms, nurse’s station, office, and store-room. (see figure 9). Beside each bed there was a cupboard and a space where parents could stay on a fold up bed and one chair. There was usually only one extra chair per bay,
therefore opportunities to sit beside a child's bed for family members, staff or researchers were limited.

There were thirty two beds available, although the Adolescent Bay of seven beds was closed at the time of the study due to lack of funding for the additional requisite staff. This meant that adolescents were accommodated with the other children. Both degree and diploma level Child Branch nurses training at the nearby university had clinical placements on the ward during the fieldwork. Children on the ward were aged between 0 and 16 years of age. There were very few black and Asian children on the ward at the time of the study and more boys than girls. This was the usual admission pattern according to the Matron (12FN) who had management responsibility for Children's Services within the hospital. The hospital served a fairly diverse socio-economic community, with very affluent families as well as those from the surrounding urban residential areas and Local Authority estates.

Most children would 'visit' the hospital and stay in overnight for planned procedures requiring a general anaesthetic. The average length of stay for a child on the ward was just 48 hours (9FN). 'Visiting' children comprised a different group from those who were required to 'live in' (7.6.2) the hospital for 5 or more days, or needed to come back on repeated occasions.

5.2.3 The corridor

The corridor linked all areas of the ward and was accessible to all, including visitors after negotiating the intercom. Nevertheless, it was sometimes used as a 'private space', where information could be shared away from the onlookers (witnesses) in the bays. In the bays, with the beds on either side of a small space, it was easy to see and hear what was going on with the others on the ward as children and parents remained fairly static at their bed spaces. The corridor was also quite busy, but any other people passed by and a degree of auditory privacy and anonymity could be maintained, as I recorded in my observation notes (15.07.05):

_The doctors are outside in the corridor having a discussion. I wonder if they went out of the Ambulatory Care area to be more private. Any bystanders_
would be walking past rather sharing the same private space therefore the witnessing is limited.

There were several times when I observed private consultations in the corridor as I recorded in my observations:

(The doctor) and a mother are in the corridor. He is explaining that her son has been hit either from the front or the back and has bruised his lung...His mother is tearful, red faced, anxious, hovering around the doctor in the corridor (15.04.05).

It was not just the doctors that used the corridor in this way, for example I noted the mother of cm6.52005 is talking to the volunteer chaplain in the corridor. It was as if the corridor, rather than being public could also be used as a 'space away' from the others in the bay areas.

5.2.4 Playroom

The Playroom was designed to be a safe area, a place where no medical procedures were done. It was a bright square room with children's paintings on the wall. There was a low table and a sink for painting and craft activities. There was equipment for a Home Corner, a table football game, a television and lots of videos, books, a play station and game cube. There was an aquarium with healthy looking fish.

It was explained to me by the Play Specialist that the Playroom was designed to be an area where children can make sense of what is happening to and around them, or to escape. Siblings also found entertainment here as I recorded in my observation record:

A sibling is happily painting a hat made from a cardboard vomit bowl (10.06.05).

The playroom provided a space where children, including other family members did not have to be still, or very quiet as sometimes they needed to be in the bays where there were ill children, busy staff and machines.

5.2.5 Side-rooms
There were a number of side-rooms, some were quite large but others very small. Families were left to make themselves comfortable within the side-rooms, but sometimes mothers found this difficult when caring for their sick child.

_The father of cf15.12032 is taking out the z-bed from her room and exchanging it for another in the corridor. It was broken, three of the slats were missing making it very uncomfortable for his wife and baby last night. The mother is holding the baby who looks hot and uncomfortable despite having just had Calpol (25.5.05)._  

This particular room had no windows and parents could find it oppressive:

_There is no air it seems in the room. The mother asks me if next door is free as her room feels like a prison with no natural light (25.5.05)._  

Other rooms were used for children who had had frequent or prolonged admissions and included children who were immuno-suppressed. Some of these rooms were large and could accommodate a parent easily. There was a baby unit with four cots separate to the bays.

5.2.6 The nurses' station

The nurses' station and desk could not be seen from the entrance and visitors had to follow the corridor round to find it. The space behind the desk was divided off by a curved counter, or "wall" and used exclusively by the staff. I was reminded of the interpretation of the Berlin Wall by Soyinka (2004) as "a gesture of distain." A number of chairs were behind the desk with three computer terminals and 'phones, here staff would often congregate. One needed to attract the attention of the Ward Clerk on arrival. Behind this high "wall", the staff; nurses and doctors were difficult to reach especially if you were small or in a wheelchair. I noted the impression I had of the nurses in my observation notes soon after starting the staff interviews:

_One to one the nurses are nice, but they are unaware of the impression and power that they give 'en mass' (22.9.05)._  

I found it difficult to penetrate a group of nurses, to ask a question for example and I speculated as to whether they were aware of the affect they gave. I wondered too if this
was a defence against being asked questions, much like the avoidance of eye contact I had noted in the Pilot Study (4.2.6).

Further behind the nurses' station lay the ward office and the area where staff could make drinks and the notes of regular patients were kept. I saw a child behind the "wall" on just two occasions. Once was when a baby was being held by the Senior Sister. This isolated incident was reassuring to me, and possibly others on the ward, the sight of someone usually so busy, sitting down to cuddle a child. It was an opportunity for the senior nurse to demonstrate her humanness.

On the other occasion, I recorded my surprise in my observations (21.4.05), when I saw seven-year old cm7011 holding his I.V. stand and positioning himself just by the "wall", as if he were going to walk behind it when he wanted attention from the staff.

5.2.7 Adolescent Bay

The ward had an adolescent bay, that was rarely used as such as there was insufficient funding for staff. Generally it was used to store equipment or sometimes to house one child who needed specialized equipment such as hip traction, that took up more room than was available in a bay. The ages were mixed in the bays, especially in the High Dependency Unit (H.D.U.) bay where the children required more observation and attention.

5.2.8 Treatment Rooms

There were two treatment rooms on the ward. They were used for procedures and examinations where more privacy was required. The treatment rooms were also used to contain children during more unpleasant procedures such as venepuncture, cannulations or lumbar punctures. Such procedures were supposed not to be done on beds in order to secure the bed space as one of safety. This was not always adhered to however and cannulations were undertaken on a child's bed

5.2.9 Ambulatory Care
Ambulatory Care was the first bay on the right of the corridor after the entrance and was open from 09.00 to 17.00 hours only. When agency nurses were required they commonly worked in this area. It was easier to acquire agency staff for a 09.00 to 17.00 hours shift. As children were not always admitted from this area, but sent home after examination by the doctor, staff continuity was arguably less important. However, on busy days there was a lot of movement of children, families and doctors in and out of the area. Sited away from the heart of the ward parents had to seek out nurses to ask questions. On quieter days children and their families had to wait.

Children could be referred directly from their own family doctor to Ambulatory Care, or frequent attenders could ring up then come straight to Ambulatory Care without going through Accident and Emergency. This area could be very busy, or very quiet, and held children with a range of conditions. The bay accommodated children with mild illnesses or those waiting for repeat blood tests, as well as children who were very poorly. It was a liminal space (Allan, 2007), a place of transition and a holding area for children before being admitted or sent home. It was also an area that had limited privacy (6.2.3) as it was the first area to be seen when coming on to the ward and it was an area where a lot of the initial clerking in by the doctors occurred.

Doctors moved freely between other parts of the ward, the hospital and Ambulatory Care, but children were temporarily stopped there until a decision was made as to where they went next. For some it was their first experience of the hospital, for others it was the beginning of another admission.

5.2.10 Out Patients

During my time on the ward, I also visited the Out Patients department, or as it was more widely referred to the 'Children's Unit'. The area set aside for the children's out patient clinic had not been upgraded in the same way as the ward. I described the unit in my observation record of 29.04.05:

3 Liminality is a concept I discuss later in my analysis of how illness in the children was legitimized (7.8.4).
Out Patients is organized around a ‘C’ shaped corridor on the ground floor of the hospital. Chairs are placed along one side of the narrow corridor with doors leading to consulting and other rooms coming off it. The wall in front of the chairs has toys and leaflets, a blackboard etc, much is made of the space. There are books and toys including Lego, a Galt village, a rocking horse and maze. There is an eye chart, pictures and information on the walls. There is a corner with more toys that is fenced off.

A tiny girl with lots of hair comes in. She looks at me and I smile. Soon she is called in to be weighed. The scales are out in the corridor and I feel uneasy about public weighing and the unnecessary exposure of the child to the waiting room. Although she is a room off to one side, there is not enough space to fully close the door. I can hear tears from the girl. “No point in getting upset” says the mother. “It doesn’t take much, especially at this age” (nurse)”She doesn’t like people prodding and poking”. Later they come out of the room and take a seat. The family; father, mother and child, seem to be a tense trio for a while, not interested in what is happening around them.

I noted my discomfort at being party to the child’s exposure through weighing, as she is obviously smaller than ‘the norm’ (7.6.4) and my seeing her tears. By talking about the child, while she is in front of them, the adults objectify her further. The behaviour of the family reflects their experiences of the hospital and the continuing surveillance of the child. Priestley (2003, p.64) describes a “tyranny of ‘normal’ child development” that labels and marginalizes disabled children and reconstructs them as a social problem.

5.2.11 Use of space

I was interested by the way it seemed possible to guess the role of an individual from the way they used space on the ward. The ward round provided a good example of this as I recorded in my observation notes (25.05.05):

The doctors congregate by the nurses’ station, they are quite loud and jovial. There seems to be an element of anticipation as if out to impress. The consultant is speaking quite loudly about his nieces and nephews and seems to be enjoying an audience.

I make the comparison of the behaviour of the doctors and myself in my role as researcher (20.7.05):
The doctors are on the ward today, congregating noisily. They are jolly, hearty even, male. Dr G and Dr D. They take up a lot of room, it's their space, others get out of their way. They stride, I lurk.

On occasion I misinterpreted the role of an individual. During a large ward round, I noticed a woman, who I took to be a doctor, as she was not in uniform and was following the doctor's round. She left the round to go and choose a toy from the playroom to appease a child. I was surprised and impressed with her flexibility, only to discover later that she was a specialist Health Visitor, a profession more in keeping with this behaviour. Alternatively, it could have been a reflection of her gender, although the other women on the round had not reacted in this way.

I argue that staff were accustomed to seeing children in a particular way and behaving in a way that reflected their professional background. The different professional discourses were reflected in the way they understood the meaning of dignity. For example 4FN the physiotherapist when talking about how parents might promote their child's dignity said:

"Making sure they can help out by providing bits of equipment for dignity."

The children were in the main, isolated on their individual beds. They did not come together to eat at a central table and most of their time was taken up within their bed space. My research aspirations had been influenced by inspiring accounts of interviewing children in their natural world involving "movement and activity" (Irwin & Johnson, 2005) where children were able to use their space in a way they enjoyed. For the children in this study, their space was defined by their hospitalization and did not extend much further than the end of their beds. The children, on the whole, did not present as "kinetic chatterers" in the way Irwin and Johnson (2005, p. 825) describe:

"Emerald tumbled on the sofa without missing a beat answering or telling her stories."

I could argue that the children in my study, were not in their 'natural environment' of friends and activities and learning and growing. However, for some of them the hospital had become their natural environment as they had spent so much of their lives there. Cm14010 had been in and out of hospital since he was a baby, now aged fourteen he described his pattern of admissions:
"I don't know how many times, but if I had to say how long, I've been in two and a half months, four months, the latest one was seven and a half months."

Some of the oncology patients had also had their childhoods characterized by lengthy treatments and admissions. For example cm8080 had been attending hospital every month for the last three and a half years.

5.2.12 Time.

As well as physical boundaries such as walls, daily routines provided a temporal framework. Despite individualized family centred care being the explicit aim, mealtimes were set, as were the shifts of the nursing staff. In addition to dominance of routines were the imposition of tests, ward rounds and procedures on the waiting patients and their families:

I am very conscious of the parents. They are anxious and 'twitchy'. One part of them constantly tuned in to signals about the ward: the smell of lunch, the clatter of trolleys and what that may mean, the talking on the doctors’ rounds (13.04.05).

The days of the children and their parents seemed structured around these concrete events and disturbed by the apparently random requests for tests, examinations or investigations over which the children and their parents had little control. Frankenberg (1993) comments that it is such uncertainty that is part of patients' suffering rather than marginal to it. In the ward environment both the children and their families were required to adapt to the ways in which time is organized. Holloway et al, (1998) highlight the dichotomy between the professionals being “pressed for time” and patients who seem to have “too much time on their hands”. Davies (1994) differentiates between linear clock time and process time. She recognizes both as prerequisite to care with an ideal of carers being able to switch between the two as required. Care, she concludes requires process time and too many children, too few staff and too little time threatens process time.

5.3 The experience of the research for my self as researcher
In some respects, particularly at the beginning of the research, I perceived myself to be in a similar position to the parents: less emotionally charged, but definitely in limbo, powerless to exert any influence and at the mercy of the vagaries of the ward. Despite my nursing background, I found it difficult to know what was happening on the ward, especially as no information was passed on to me, in the interests of patient confidentiality. This sense of alienation however, did enable me to feel authentic about approaching the parents and their children from a position of equality rather than as 'another one of the staff'.

5.3.1 Strangeness

I described using the notion of “strangeness” as a methodological device in the Methodology chapter (3.4.2). As discussed, I developed the construct ‘strange’ in this way from earlier pilot work. My acknowledgement of strangeness gave me the opportunity to appreciate something of the “alien” nature of a hospital to a child entering, perhaps for the first time. Too much familiarity and feeling of comfort with any research setting can blind us to its quality and to some of what is going on. I was able to take and use this understanding of strangeness when I undertook the main phase of the fieldwork.

It has been the study of the surprising, the odd and the unusual that enabled me to see the way staff, children and parents alike work to ‘normalise’ the strange, for example through rules. Where dignity is concerned there seemed to be a complex set of rules for example, to do with preventing the exposure of bodies and body functions of bodies as a way of coping with challenges to socially constructed notions of extrinsic dignity. I have discussed this in more detail when I discuss the performance of dignity (6.11). Nevertheless, strangeness seemed to have an effect upon the control and power relations within this setting. During the study I examined the reactions and adaptations children experienced and expressed in this sometimes, alien environment and in turn how this influenced and affected their dignity. The strangeness and associated non-understanding of meaning could render children and their families and their researcher powerless.

Children themselves may also be considered strange. It came to my notice that although I was not allowed knowledge of a medical diagnosis, I was invariably made aware when
there was a child with special needs such as a learning difficulty like Attention Deficit Hyperactivity Disorder (A.D.H.D.), Asperger's syndrome or autism (6.5.6).

I speculated that my presence as researcher must have been 'strange' to the staff (4.2.5). Previously, in the Pilot Study, nurses had expressed concern at my surveillance of the ward and what it might mean for them:

"You'll be watching the nurses" (S.N.Jac.).

My role certainly provoked suspicion, particularly among the nurses. Perhaps the fact that I was not a children's nurse added to any misgivings that they may have had.

I was conscious of being a stranger to the children in the research. This was in light of children being made aware of 'stranger danger'. I was careful not to abuse any perceived authority as a ploy to get children to talk to me in a way that they would otherwise not do.

5.3.2 Control of access

Access to the field was quite difficult at the level of the ward with the ward sister (17FN) acting in a protective and defensive way on behalf of the other staff (3.3.1.2). In my initial meeting with her in January 2005, she seemed to be safeguarding the staff. She thought they might feel criticized when they “have a lot to put up with” and they were “constantly on the go”. She stressed the busyness of the ward by saying that the occupant of one bed could change four times in a twenty-four hour period.

As a condition of my undertaking research on the ward, I agreed to report to the nurse in charge on arrival and she would tell me if there were any patients that would not be suitable to approach. Thus to some extent the participants could be defined by the nurse in charge, and some nurses allowed me more freedom in whom to approach than others. I discovered that this censoring could sometimes inhibit a relationship that I thought was developing between a child and their family and me.

17FN is on the ward today. She has asked me not to speak to two of the children I had hoped to talk with today. I do not think it is because they are ill,
I wonder if it is because they are in some way dissatisfied, or that I might make things worse. I had told one of them that I could interview them today, now I will feel awkward because I will have to avoid them (21.04.05).

In this situation I felt obliged not to approach either family, on that occasion, as it became apparent that a possible complaint was ensuing. Nevertheless I did record an interview, at a later date, with one of the children and his mother.

As I have described in the methodology chapter, I was not allowed access to the medical notes of the children (3.3.1.2). Both the consultant and the sister of the ward specified that this was unnecessary for the purposes of the research. This was in spite of being a registered nurse, with an Honorary Contract with the hospital and clearance from the Criminal Records Bureau. This meant that I did not know the diagnosis of the children. However the children and their parents usually told me spontaneously why they were in hospital, if not their diagnosis.

Nevertheless secrecy itself could create problems. Some children had a very clear understanding of their treatment. They could explain at length the number of treatments they were going to have, when they were going to finish and the names of the drugs. However, as I discovered, they did not necessarily have much knowledge about their disease itself. For example, I interviewed an eleven year old boy who told me all about his drug therapy and immuno-suppression, but it became apparent, some way through the interview, that he was not aware of his serious diagnosis. When involving children in making choices about their treatment, it should not be assumed that they have an equally good understanding of their disease process, implications and prognosis. This was equally true for me when interviewing children and I had to take care that I did not divulge anything of which they were unaware.

5.3.3 Power and “nosiness”

Both as a researcher and as an “other” person on the ward, I was very aware of power and power differentials. My review of the literature had highlighted dignity as dependent, in part, upon the principles of autonomy and respect. At ward level, I became aware of how power, and specifically, the imbalance of power had the potential to impact on the
way dignity was maintained and promoted, or undermined. As a researcher I was keen to ameliorate this disparity.

However, the dilemma of the need to "collect data" and my commitment not to exploit the participants in any way was constant. I was conscious of my position as both 'adult' and 'researcher' in my interactions with participants. I questioned myself continually "Is this legitimate research or is this nosiness?" I had become particularly sensitive to "nosiness". It had not taken me long to became aware of the felt impact of another's nosiness when talking with mothers of children with complex health needs. When I asked questions of parents and children I asked myself first: "why am I asking this question?" "Is it relevant to the research?" "Is it for my own curiosity? Nosiness? Or voyeuristic tendencies?" "How does asking this information affect the dignity of the child and their family?" "How does this information affect me as a researcher?" "Does it put me in a more powerful or knowledgeable position than the child and, or the parent?"

Throughout the research I endeavoured to work with integrity as a researcher and as a human being. Asking questions and recording observations was very possible in this captive population, but just because I could, I needed to ask myself "should I?" This notion of nosiness caused me some difficulties as a researcher. There were times when to stay and listen to a dialogue, even though consent had been freely given, felt like nosiness. Below is an extract from my field-notes (10.06.05) when I opted to remove myself from the scene so as not to contribute to the exposure and exhibiting of a child and her mother:

_Mcf14.12045 is talking to ccf14.12045 (the mother of a child is talking to the carer). The ward round gathers around the cot. I think that other mothers are tempted to stop what they are doing and listen in to the doctors. Mum is describing a pattern of fitting she has observed. I take myself away it feels like prying._

Parents and children were usually happy for me to be around (observing) taking notes when they were on the ward and gave verbal consent. On one occasion, I felt reassured when my presence was objected to. I recorded in my field-notes (8.6.05):

_I started to speak to a mother (mcf4049) when her four year-old turned her back. I interpreted this as a refusal and explained this to her mother and I left_
I later saw the girl pull the curtain around her bed, as if to assert her desire for privacy.

I felt encouraged that my approach had indeed enabled her to refuse to take part.

5.3.4 Positioning myself as researcher when interviewing the children

Prior to the main phase of the fieldwork I had anticipated being able to get close to the children in the study and to be able to interact with them more through play and activities. I had seen opportunities at the Pilot site for interactions in the teaching/play area. Further reading had given me ideas for participatory models of research with children (Greene & Hogan, 2005; Lewis, et al. 2004). However, the children spent most of their day by, or on, their beds with a parent in close proximity and the turnover of patients was very fast. I felt very direct and formal when I introduced myself to a child and their family and I would have preferred to have been able to approach the children in a more relaxed and natural manner. Similarly the parents were often quite anxious when I first met them and I was very careful not to pressurize them into talking to me. I was conscious that many would like to be seen as 'good' parents and so be easily persuaded.

I found that interviewing a child with their parent seemed to give the children confidence to speak more about their experiences. I surmised that this would also be the case with interactions with the hospital staff. The way child and parent had got used to talking with the staff could be easily replicated with me as researcher. I had noticed that doctors usually directed their questions at the child, but more commonly than not, they were answered by the parent or carer, with whom the conversation continued. I made a point of starting with the child and inviting the parent to speak afterwards. I thought this approach gave me the opportunity to build a rapport with the child first. However, I found that even using this approach, I had to be careful that I did not unintentionally favour communicating with the parent:

*I have a quick chat with cm12095 and his mum before the nurses come with a gown to get him ready for theatre. He seems fairly relaxed, talking about golf. Mum asks me about my own children* (14.12.05).
In answering about my own children this somehow changed the alliance I was trying to build with the child to his mother. By identifying myself with the mother through our shared experience of being mothers, I effectively curtailed the relationship I had with the boy. Thus although the parents can facilitate communication with their child, their presence also mediates the communication that becomes somewhat indirect. This has implications for the medical, or nursing interview following a family centred approach. (7.5.1). A triadic relationship results between child, parent and heath professional (6.4; 7.5).

I am conscious that I could be seen as having colluded with the dominant model on the ward of family centered care and replicating the power relations. I discuss this later with particular attention to the implication of replicating a triadic pattern of communication that risks displacing the child from core of the research (7.5; 8.6). I tried to work as fairly and ethically as possible and I have heard the voices of the children in the study. The ethnographic approach rendered me particularly sensitive to the context and how this may have distorted their story. Nevertheless children were able to give their opinions on what was happening to them, albeit with a parent present. They were able to talk about issues such as dignity, or feeling uncomfortable, or their likes and dislikes despite dignity seeming at the outset to be such a nebulous term. I conferred on the children in the study, as I hope I do with all children, a “sense of present value” (Christensen and Prout, 2002). By this I mean, I have honoured the current worth of the every day existence of each child rather than seeing them as part of a process, on the way to adulthood and in relation to adults.

Of course, I had to be aware of the parent and the parent child dynamic and the way the child may choose to sensor what they said. However the parent could often facilitate the discussion and seemed to give their child confidence in speaking to me in a way that would have been difficult given the limitations of time and space. This is a point to which I return (5.4.2).

5.3.5 Construction of children

As an observer, I was interested in the way children were constructed on the ward and in what sense their illness and hospitalization reconstructs them from a child to a "sick
child". The children interviewed had had differing experiences of hospitalization. Some were on the ward for an overnight stay following an operation or procedure. At the other end of the spectrum, were children who had had repeated or lengthy hospital admissions (<11 weeks at time of interview) and their childhood had been characterised by a considerable time spent in hospital and, or unwell. This reconstruction of the child was noticeable in children who had long standing health problems.

As children were observed on the ward out of context of their home, family, friends, possessions and interests, it was difficult for them to establish and sustain a sense of self and present their selves to others. In the absence of such individual and personal effects children were less able to control the way they presented and were perceived by others. This in turn could affect the way they developed their own sense of self (Waksler, 1996). Adults maintained control over dress, activities and peers and contributed to the limitations posed by illness. I argue that children were reconstructed as "sick children" in a vacuum from their everyday defining lives. This was a tendency I found myself slipping into. I realised that, in some instances, I found it difficult to hold another construction of the child in front of me, for example, as they would be out of hospital.

I was in the side room of cm11088 and he showed me a picture of him in his football team at school. He and his mum explained that he was a keen football player. I realized that I had constructed him as a 'sick child'. I noted my surprise that he, only a few weeks ago had been playing football with his friends. Now he is hunched and his face altered through steroids (9.12.05).

This difficulty in seeing the child in his/her entirety is problematic if one is trying to acknowledge the individual child.

I became very aware of my own response to twin babies when interviewing their mother, as I recorded in my observation record, 15.04.05:

I interviewed the mother of cf4.12007, who is one of twins. The other twin is staying in hospital too so that the mother can continue feeding. Cf4.12007 looks a bit odd compared to her sister. I am not sure whether she can see me. I feel that I should react to both twins equally, to make a fuss of both of them in the same way and not to discriminate. I am aware of how the girls could be compared in the future if cf4.12007 has something ongoing problem. I am trying too hard, it is much easier to coo with a baby that responds back readily.
I noted the ease at communicating when one experiences reciprocity of communication I also sensed a disingenuousness about my interaction with the affected twin, a sense of “trying too hard”.

5.3.6 Being human

As a nurse I sometimes found it difficult to be on the ward and not have the comfort of being obviously busy (5.2.5). The times that I most enjoyed related to just ‘being human’ and feeling a sense of connection with others. I enjoyed moments when I could engage with the children in a way that seemed natural and not contrived through the research process. I noted these in my observation diary as they gave me, and I hope the child, real pleasure. For example, cf8050 was a girl with special needs who did not communicate verbally:

Cf8050 is in the Playroom painting. She mimes something to me with a pen as she paints. I try to understand what she means. I get it wrong and she responds by looking very cross and stamping her foot. I try about three times. At the back of my mind I wonder what she will do when she gets really frustrated with me. However on the fourth attempt, I realize that she is asking me to write her name. I check her name band for the correct spelling and put it at the top of the picture. She is very pleased and runs back to tell her Mum with the picture still wet. I follow her and explain to them both that she could let her picture dry in the Playroom. I feel really pleased that I have made some kind of positive impact (10.6.05).

On another occasion (13.07.05) I was in the baby unit and looked in on a two-year old girl with a view to interviewing her mother who I met earlier, but she was not there:

I go and say hello to cf2054. She talks to me and shows me her doll and her teddy as if she is saying “This is what I am about – get to know me…”

In the same unit, but later in the day, I go to see cm22.12053 who is twenty-two months and his mother:

Cm22.12053 lies in his bed his mum has just turned away after changing his nappy. He has one leg in a cast and a hip spica. He kicks his toy elephant with his foot. I ask him if he wants it, he doesn’t answer. I cautiously pick it up and offer it to him. He takes it and moves it quickly to his mouth. I move away. I seem to have supplied him what he needed at that moment (13.07.05).
On 14.12.05 I make an observation of Cm0190 was in Ambulatory Care, very wheezy:

Cm0190 is quietening and looking at me intently. I do not want to intimidate, so I look away so that he can go on staring unchallenged.

I found these moments of communication rewarding, aside from the research itself. At other times, such as when people were in distress, it was more difficult for me to know quite how to respond as I recorded 10.6.05:

"It's a shambles" she says (mcf14.12045). I am not sure what she is saying, she looks very unhappy/distressed/tired/disoriented, I am not sure. I feel unsure as to how to respond, as another mother, as a hospital representative who in some way could assist with the system (almost like a nurse) or a reporter, hounding her for a good story.

On another occasion I recognized one of the mothers as someone who lived near me and she recognized me. She wanted to be interviewed:

After the tape she (mcm0648) says that she has had a bad feeling about this. 'You never think it is going to be your child'. She fills with tears, I feel myself welling up a bit. I felt uncomfortable and unsure of the distance I should keep and how I could and should help appropriately (8.06.05).

This encounter highlighted boundary issues between my role as researcher, professional, another mother and at a deeper human level. I was careful not to draw her out, nor to try and offer support. I just fought to contain her. She was calmer after talking but I do not imagine she felt helped

Most of the time I felt very separate from the staff and I liked to maintain a position away from the staff to observe the dynamics of staff, visitors, parents and the children. Nevertheless I did appreciate moments of kindness, normality and humanness offered to me:

"There are some doughnuts and strawberries in the staff room if you would like one...my treat" says the Play Specialist. I am chuffed by his kindness and surprised (15.07.05).
I reflected on just why these moments, that I have included in my construct "Being Human," were so important to me. I speculate that my reaction is in parallel to that of the children and their parents (6.13; 7.13). I wonder if in an environment so alien, outside of our control and devoid of comfort it is the human element that we all crave and I hold my own thirst for human connection as a tentative insight into the experiences of the children.

5.3.7 Entering the children's worlds.

As described previously (3.3.6.2), in order to hear the voices of the children I approached the children in a more direct manner than I might otherwise have done. However, I always approached them in the presence of their parent in an attempt to be less threatening. I was ever conscious of my role to do no harm and not to open up a child, or parent, only to be able to offer insufficient support. There were occasions when I felt I could enter into the child's world on their invitation.

Being familiar with the worlds of the children from having my own children, in terms of popular toys and crazes was helpful to me. Below is an extract from my field notes (19.05.05) with a six-year old boy (cm6024) who had been confined to a side room for several weeks. He had been very ill and had previously not been well enough to talk with me.

I go into cm6024’s room. He is much better. He approaches me with a light sabre, which I avoid and we have a quick chat about Yoda our favourite Star Wars character...

Later the same day I interviewed him with his mother present. He talked about his experience over the last few days and weeks:

R: "...and what about the nurses and doctors, have they been into see you much?"
C: "I've attacked them with that light sabre and squirted some of them?"
R: "Did they have light sabers with them?"
C: "No"
R: "That doesn't sound very fair!" (laughing)
C: "They didn't even have squirtsers with them!"
R: "Oh. So have they been nice?"
C: “Yeah, (pause) Yes except when they had to put medicine in 'cos some even tastes horrible”

I interpreted this as ambivalence about the presence of the nurses. On the one hand they were nice and he was pleased to see them and yet they brought horrible medicine. He was frightened and defended himself, as he had with me, by testing their responses to his 'attack' with the light sabre.

5.4 My self and my part in co-constructing the data with the participants.

It was important to be both active in acknowledging my 'self' and what I brought to the research and passive in terms of reflecting upon the role I adopted. In the analysis of the data it was important to be as explicit as possible regarding my self throughout the research process. My self influenced my choices and trajectory of the methodology as well as each observation and interview and consequently how the data were constructed and analysed.

5.4.1 Emotion work of the researcher

The work of reflection on first person fieldworker accounts is as essential to the analytic process as the analysis of other data sources such as interview transcripts (Young & Lee, 1996). The emotion work involved in being a researcher, in the setting of a children’s ward, and being friendly, approachable, non-judgmental, interested yet not overly intrusive – the “ideal researcher,” is considerable. Such work, therefore has its own “feeling rules” of emotional convention (Hochschild, 1983). Feeling rules are dependent on context and Smith (1992; 2.2.7) discusses how the ward sister sets the tone of the ward and, in so doing determines the feeling rules. Hochschild (1983, p.57) describes how to understand feeling rules by “focusing on the pinch” between “what do I feel” and “what should I feel.” There is a wealth of data to be collected and analysed reflexively between these two positions.

Theodosius (2006) critiques the work of Hochschild in arguing that she does not address emotion hidden from cognition. She argues that in her thesis of emotional management and labour, Hochschild (1983) underplays the importance of hidden emotion in social context within which they arise. Theodosius uses an ”interactive and unconscious
approach" to the analysis of her emotion during empirical work to “try to identify hidden and visible emotional processes in order to understand how they impacted on emotional labour” (p.901). In other words she attempts to recover emotions hidden by the processes of emotion management using psychodynamic theory. It is these hidden emotions that once retrieved can offer further insights into the research process. Theodosius uses the psychoanalytic devices such as transference\(^4\) to explicate interactions between individuals and understand processes within. Although not pivotal to my analyses, I have occasionally used some psychoanalytic principle to offer an alternative construction of events.

5.4.2 Using a person-centred approach

Central to the way I conducted myself was to believe in and adopt a person-centred approach. I mentioned earlier (3.2.1) that I have been influenced by Carl Rogers and his philosophy of person-centred therapy. He describes three “core conditions” that he argues are necessary and sufficient for a “therapeutic relationship”. These are: unconditional positive regard, congruence and empathy. His approach to therapeutic work has been influential in other spheres including nursing, social work and research. A person-centred approach in therapy or caring relies not on theoretical devices but on the relationship between therapist and client or nurse and patient. Unconditional positive regard implies that, in this case the researcher, is free from judgments of the participant and is able to accept them. The condition of congruence implies that the researcher is genuine, that they are self aware and in touch with how and what they are feeling in the moment. In the therapeutic relationship, these feelings are made available to communication directly with the client. Empathy, in the Rogerian sense, is the understanding of the subjective perceptual world of the other (Thorne, 1992). In particular I considered a person-centred approach to be appropriate to undertaking this research because of its insistence upon the centrality of subjective experience. In addition, this approach disputes the therapist, or in this case researcher, as expert and asserts a mutuality of human relationships.

\(^4\) Transference phenomena occur in all relationships and are paid particular attention to in psychoanalytic approaches. They relate to a repetition of previous emotions and ways of relating to significant people, for example parents, and transferred to another situation (Jacobs, 1988). Unacknowledged transferential feelings can hinder client progress in therapy and, in the case of research, allow researcher bias to go unchallenged.
5.4.2.1 Testing meanings.

The person centred approach has been associated with a reflection of feelings, however, Rogers himself clarified this as “testing understandings” (Thorne, 1992). Adapting this to a researcher/participant relationship, the researcher can test the meanings of the participant as a way of ensuring the thoughts, feelings and understandings of the participant are recorded accurately. In this way the process of concurrent data collection and analysis begins and credibility is assured. Later, during the more detailed coding, I could be confident that I had understood and confirmed my understanding with the participant at the time of the interview.

On re-reading my interviews, I recognized that some of my testing of understandings were more accurate than at other times. On reading the transcripts I found times when I did not check out the subjective meaning of the participant at the time and found myself left with questions over what that participant really meant. In this example I am talking with an eight year old girl who had been hit by a car and fractured her femur. She was talking to me about a visit from her friend and the homework she had brought in with her. My expectation was that she would not have appreciated homework. Although I picked up on the girl’s boredom in hospital I failed to identify and test with her the underlying anxiety she hinted at:

C: My friend came in the other day with her mum, but she brung me some homework that my teacher gave her to give to me.
R: How was that? Were you pleased to get that?
C: Yeah
R: Was it quite a relief to get some homework?
C: (Nods)
R: Because there's not much to do?....Or you don't want to get left behind?
C: No it's just, I don't know. I've missed my tests, my SATs tests. They started on Monday. They finish them tomorrow but...
R: So you were all ready for that?
C: That was gonna be on my school report and now I've got... I don't think I'll get a school report this year....

R: Have you been able to chat to the other children?

Rather than following her, I chose to redirect the interview to follow my own interest in what she was saying.

At other times, I was more able to test my understanding of what the participant was saying and be more 'person-centred'. For example in this extract from my interview with cf14047 who had come in for some corrective surgery to her foot:

R: And what's it like being a fourteen year old on the ward?

C: "Well, it's strange because I am the oldest, but I'm not sure whether I will be by the end... by being round smaller kids a lot of the time. Not that I have been here that long.

R: What feels strange?

C: Because there are no other kids my age. I know it sounds stupid, but I kind of feel like I have got to be strong 'cos I don't want them to think it's really bad.

R: So you have to put on a show for the younger ones

C: Well, not put on a show, just like...

R: You wouldn't want to cry in front of them

C: No

R: Because you'd be worried about how they were?

C: Yes

This way of checking meanings also has the affect of acknowledging the importance of what the participant is saying. My concurrent interpretation of meaning is offered back to the participant for their affirmation. The expertise and power is shared and the interview relationship is more inline with an equal partnership of two participants engaged in the process of information gathering and explanation. In the second example, by following and acknowledging what the participant was saying I was also able to learn something of the emotional work (2.2.7) this fourteen year old had undertaken (7.12.3).
Meaning could usually not be confirmed after an interview because of the short and intense period of hospitalization experienced by the majority of children. This meant that my reflections on a transcript were subject to my own bias, and arguably my own transferential feelings. Thus I have attempted to scrutinize my interpretations following events by attending to some of my unconscious (at the time) emotions and, on occasion, using the psychoanalytic concepts of transference and projection (6.5.1.1) as “tools of analysis” (Theodosius, 2006, p. 818).

5.4.2.2 Limitations of a Rogerian approach to this study

The incorporation of the philosophy of a Rogerian approach into my research was challenging. It was difficult to shake off the guise of an adult with authority on the ward when approaching the children and their parents. Before speaking I was aware of the parents and children sitting up straight, adopting the stance of ‘one about to be interviewed’. It was difficult to portray, in my manner alone, that I was not someone with authority, but someone who would like to hear what they had to say about the topic of dignity. The very word ‘dignity’, on occasion, could drag a participant from the reality of the world of worry and concern about being ill or having an ill child into a theoretical debate that they could find at odds to their real situation. Some participants could have found my questions threatening, as if they had to come up with the right or clever answers. This included the staff as well as the children and their parents.

In a counseling relationship, the ‘client’ chooses to speak with a counselor. They can often even pick the style and approach with which they feel most comfortable, or to be most beneficial. This is at odds with my initiation of the research interview and this is where a faithful Rogerian approach does not fit. The agenda of the interview was set, however loosely, by me as the researcher. The agenda was not the participant’s. However much I was able to follow the participant in their explanations, I was the one who directed the line of inquiry. On the whole it was I who asked the questions. Ultimately, what I learned from them was for the purpose of my research. I would like to think that our exchanges in some way helped the participants feel listened to, that they and their views mattered and that they were understood. To exploit the participants would have been an assault to their dignity and out of step with a grounded theory approach.
A person-centred approach being grounded in the here and now, as such offers less to the researcher away from the context of the researcher/participant relationship. My biases recorded in the data could go unchallenged. However, insights from the alternative psychoanalytic model, I propose, can be employed to challenge assumptions.

5.4.3 Meaning in three way (triadic) interviews.

As with all qualitative interviewing, there was a tension between me guiding the participant rather than letting them tell their story in their own way. In this research my interviewing was rarely one to one but three way with the parent. Alldred (1998) describes how parents can scaffold the stories of their children by leading the child in a complimentary way and that this scaffolding can add to the "richness and completeness of the story that may not otherwise have been accessible (Irwin,& Johnson, 2005).

Below is an extract from an interview with an eleven-year old girl (cf11087) who is explaining how she feels about being on an open ward and how she managed her experience. Her mother joins in to help:

C: "...if you are feeling unwell and you see other people, may be it feels like you've got company and it's not just you. But then when you feel better, it's sometimes when you are on your own...."

Her mother joins in:

M: "Yes, she didn't like seeing any of the other children looking awful...."

C: "Right so we had to draw the curtains so we couldn't see them"

I was aware that even after a short time in hospital, the children and their resident parent had learned an approach to the interview situation, where the parent supplemented the answers given by the child. For example, parents frequently clarified factual information as they might do in a doctor child interview.

On occasion a parent might clarify meaning that was not obvious from the child's statement. For example here a fourteen-year old boy who had spent a considerable time in hospital describes a time when he felt embarrassed when swabs needed to be taken.
R: "Swabs from different places?...from different places of you?"
C: "Yes, (knowing look) from different places"

I am curious, as to why the event was so humiliating for him and the conversation continues around how it could have been done better, until his mother interjects:

M: "They were female"

Children would, on occasion, respond in a way that betrayed little emotion and so I found it difficult to assess the importance to them of what they were saying. Here an 8 year-old girl explained to me what had brought her into hospital. (Her mother was not present):

R: "Did you have a lot of pain from your leg?"
C: "Yes"
R: "Was it really horrible pain?"
C: "Yes"
R: "Did you think, 'Oh I have broken my leg!' ?"
C: "Well, my friend's mother already knew that because she saw the bone"
R: "Were you crying?"
C: "I was screaming a bit"

In contrast when parents were there they tended to either exaggerate or play down the emotion behind the child's response in the interview and therefore skew the subjective importance of the response.

In a variety of ways the parents were often very active in co-constructing the story of their child's illness. Here four and a half year old boy is reminiscing with his mother at home about his time spent in hospital aged two and a half. His mother is describing their trips to the hospital in the middle of the night:

M: "...kind of adds to the trauma of it all somehow"
R: "Do you remember those night trips (child's name)"
C: "Yes and I remember that time when we went out in the middle of the night with Dad, you remember?"
M: "Aha"
C: "In the Subaru...maybe, or the old shiny car"
M: "Yes, it was the old shiny car"
C: "...and we used to go up in the car and you used to say 'Drop me off' Mummy? And Daddy would drop us off at the front doors of the hospital, do you remember? Then he'd go and park the car and we'd go up to the ward and he would meet them and he would meet us there, wouldn't he?"

Sometimes, as in this case, the interview and discussions generated seemed to be a pleasurable and affirming process for the child. It was as if the child remembered, with a almost a sense of nostalgia, a threatening time from which he emerged safely.

5.5 Summary of Chapter Five: The Voice of the Researcher

In this section I have reflected on the environment or setting for the research and have tried to impart the atmosphere as well as the physical aspects of the ward. I have done this by reflecting upon my emotional reactions to the research setting. I discussed the areas of the ward and the use of space by the different participants, including myself as researcher. I also discussed the way time was managed by staff and for the children and their parents.

I have explored my experience of the research as researcher and outlined some of the challenges I faced gaining access on a daily basis. When there was resistance to the research it came from the staff, particularly the nursing staff. I adapted my approach to incorporate their misgivings. I have described some of my feelings of powerlessness and how I imagined this to resonate with the feeling of the children and their parents.

I have described how I found it useful to tune in, rather than tune out the strangeness around me, using "strange" as an ethnographic device; to attend to the unusual rather than to accommodate it as part of every day existence. In this way I could interpret and understand the meanings and norms of the ward culture. I experienced a tension between the urge to collect data and the conviction to research in a non-exploitative way in keeping with my commitment to dignity. I struggled with my own nosiness and personal integrity.

I sometimes found the role of researcher very challenging. The most rewarding episodes were when I felt I had engaged with a child at the level of a fellow human being, when I was not doing anything to them or getting anything from them. At times I felt restrained in
my role in reacting in a human(e) way to some of the emotional hurt of the parents. No doubt this is part of the dilemma faced by the staff as they engage, moderate and distance themselves in their daily work. When I experienced the kindness of another, I was very grateful.

I have reflected upon the emotional work involved in the research process. I have explored the concepts of feeling rules to offer insights in data and I have also acknowledged the use of a psychodynamic approach to interrogating data.

Finally, I have described how I used the philosophy of a person centred approach to structure my ‘self’ as researcher. I have used this to determine my “way of being” (Rogers, 1980) in the field and have reflected upon how this in turn influenced methodological decisions through to determining the direction of an interview. The level playing field approach to person centred work is in keeping with the idea of children, families and staff as participants, in the research. During the discussions with participants, I found the idea of “testing meaning” to be particularly relevant as a way of understanding and recording the meanings of participants. This has been made more transparent by the way my data have been co-constructed with staff, children and their parents.
Chapter Six

Findings

The voices of the staff.

6.1 Introduction

This chapter represents the perception of dignity and children in hospital from the perspective of the staff involved in their care. In the previous chapter I set the scene in which the research took place. I reflected on my role as researcher and my experience of the research, including my analysis of the data. In this chapter I return to the context for the research, this time from the perspective of the staff who worked there. I explore the environment, the changing roles of the staff and their relationships to the children and their families, the construction of the children and return again to the power differentials between participants in the study.

In the second part of this chapter I explore the meaning of dignity for the staff. I have coded participants in a similar way to the children to include gender, occupation, allocated interview number. I have included a staff data sheet for reference (Appendix 7).

Throughout the chapter I have used the themes I identified from the data as headings by which to structure my account of what the staff said about dignity. By synthesizing the comments of the staff with observations of their interactions on the ward, I have identified themes that are central to the meaning and understanding of dignity and children in a hospital ward. I have used quotes chosen for their typicality (Strauss and Corbin, 1990) from the interview transcripts to illustrate my discussions.

Part I: Context

6.2 Environment

Staff respondents noted the importance of the ward environment to the well-being of the children and their families. As in the previous chapter, the 'environment' described here includes, not only the physical layout of the ward, but also the noise and the smell and the general atmosphere, described by the Health Care Assistant 3HCA as 'the vibe'.

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The consultants and the senior nurses had been involved in designing the ward. Through focus groups with parents, and talking with the children, they were able to identify what they wanted from a newly designed ward. The more senior staff commented on restrictions of resources in attaining the optimal environment. The ward was newly opened at the time of the fieldwork. Ward staff were complimentary about the layout and saw it as an improvement on the previous ward and facilities. 14MN spoke about the facilities for parents:

"We have a place for them to sit and read, a coffee machine, snacks machine, they are welcome to use the restaurant downstairs...proper temporary bed rather than a chair."

Staff described the ward environment and the way they used it in their care of the children and seemed proud of their 'new' ward. Nevertheless, some staff identified that the hospital ward could be a frightening place, for children and their parents:

"And it's a scary environment to come to hospital, especially if your child is very ill" (1MN).

12FN spoke about how the admission of her own son to the ward had enabled her to see the ward through another lens and was able to identify shortcomings from the perspective of a parent.

"There's no sign to show where the reception is. We have been here a year and I never noticed that till the other day" (12FN).

For planned admissions, children were invited to a pre admission visit in an attempt to familiarize them with the ward, but these were not routinely taken up.

6.2.1 Private areas

There was recognition for the need for private areas for children and their families amongst the staff. More cubicles had been incorporated into the new ward as a result of the focus groups with parents. 1MN said that he used "more private areas" as required, rather than accepting the compromised privacy of the ward. Several of the respondents talked about being able to go somewhere more private if the topic was "sensitive":

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"If it's a sensitive issue, then it shouldn't be discussed on a ward, all these wards (bays) have six beds in them, they should be discussed in a single room." (16FD).

I asked 2FN: "Who defines whether it is a sensitive issue?" to which she responded:

"If there is a family and we are querying an NAI (non accidental injury) or anything that's a child protection issue or teenage girls with abdo. pain and you're wondering whether they might be pregnant."

The control of these discussions were with the doctor, or nurse and it was up to them to decide whether a topic was sensitive and necessitated moving to another area. The child and the parents were unaware of the nature of the discussion until the questions started, so they were not in a position to request, or even agree to, going somewhere more private. Hence, as I observed, they could find themselves talking about something they would rather not on an open ward (7.10.3).

Procedures were not undertaken at the child's bed in an attempt to keep the bed as a safe place (although this did happen in Ambulatory Care), or in the Playroom. Instead children were taken to a treatment room or side room.

6.2.2 "Protective environments"

13MD advocated the use of, what he called, a "protective environment" such as the two treatment rooms thereby:

"allowing the child to express its emotions or concerns whether screaming or crying in a protective environment rather than showing them up on the ward."

Thus emotions could be contained and kept private and managed by the physical environment.

Sometimes they were not able to use more private areas because of the pressure of time or staff, or as in this case the rapidly deteriorating condition of the child:
"I wanted her to be moved into a cubicle 'cos it was all sort of going off, but we had to do the procedure there and then sort of because of her medical condition" (6FN).

Treatment rooms had the effect of protecting the child from the uninvited attentions of others on the ward and letting them express themselves without an audience (7.10.3). This sequestration of children for procedures also protected others from witnessing potentially fear inducing events (7.10.6).

6.2.3 Ambulatory Care

The Ambulatory Bay was the first bay on the right as one entered the ward. The context of the Ambulatory Bay is somewhere between a waiting room and a ward for the patient. It was often their first point of access to the hospital and the most public area of the children's ward. The Ambulatory Care bay was ambiguous for the child and parent as there they had not been fully admitted into the ward, it was a holding bay where their illness was either acknowledged and they were admitted, or they were discharged home.

For the doctor, however, it was very much part of the ward and on the whole they continued to act as if they were on a ward. However, there was a subtle difference in the behaviour of staff in the Ambulatory Care Bay and this was reflected in the way staff respondents spoke about it. For example, staff nurse 6FN was talking about changing babies and dignity when she said:

"They don't really seem to think, 'oh, pull the curtains round. I mean some people will do it openly if they are in Ambulatory Care."

It was as if the rules were somewhat different and less rigid in Ambulatory Care (6.2.1). This, I suggest, reflects the ambiguous nature of the Ambulatory Care Bay, as if not fully part of the ward. Ambulatory Care was the most easily observed area for visitors to the ward because of its position beside the entrance. Despite this, least attention to the rules of pulling curtains and exposing babies and children was taken.
6.2.4 Strangeness

From my initial pilot study I was struck by the 'out of the ordinariness' of the hospital ward, especially for a child (3.4.2). The strangeness of the hospital environment in the main study was acknowledged by some of the staff respondents such as 8FN a specialist Health Visitor who described it as:

"...a hugely ‘alien’ environment".

1MN also appreciated that the children could feel uncomfortable in a foreign place:

"...It is also having it understood that they are in a strange environment and its not the same (as home) and a lot of children don't want to be here" (1MN).

An aim of respondents was frequently described as keeping things as normal as possible, as if to protect them from the strangeness and routine could counteract the strangeness of the environment. For example, 7FN stated that one of the things that was really important for children in hospital is to:

"Try and continue as much as they normally would at home."

Similarly 1MN said:

"Having an environment that is as close to home as possible I think is a big one".

As an observer, the hospital environment seemed impossibly different from the home. As detailed in the previous chapter Menzies Lyth (1982; 5.2.1) describes how there are important physical and psychological differences between the hospital and home for children. Staff worked to overcome strangeness and replace it with normality. Physiotherapist 4FP described how normality could be promoted by:

"...providing wheelchairs so that they can go down to the canteen with their brothers and sisters when they have tea. Something like that can make a big difference to a child"
I wondered whether staff underestimated the impact of the strangeness of the hospital and the extent to which it differed from the experiences of the child at home and outside hospital. Although they recognized the hospital as 'alien', they admitted not always appreciating the environment as a child might. 12FN explained:

"I think we are familiar with the ward, so you tend to shut off and you don't see as much as you do when you walk into it for the first time."

She was so familiar with the ward environment, it was not until her role changed and she re-entered the ward as a mother, that she saw things differently.

This acquaintance with the total environment extended to medical procedures. Experienced junior sister, 2FN talked about her familiarity with procedures and how she had noticed that her reaction to them was very different from the student nurses who were seeing them for the first time:

"Sometimes with students, you show them how to hold a child for an LP (lumbar puncture) and they are horrified, but this is what I do on a regular basis."

She did not make a reference to how parents of children reacted. Staff appeared to get habituated to the environment and to hospital activities. The sociological concept of habituation is concerned with the normalizing of events of activities that would otherwise be thought of as strange (Woogara, 2005). In psychology, the notion of habituation refers to the progressive diminution of a behavioural response with repetition of the stimulus.

6.2.4.1 Strangers

The children had to meet a lot of new people and allow them to talk to them and examine them in a way that would not normally be done, or thought of, and shown to the child as acceptable. Nursing staff were sensitive to this, 8FN said:

"All these different people coming in, they could be anyone as far as they are concerned."
5FN said:

"It is a really scary place to be in hospital. You’ve got these people whizzing round, coming to see them, different faces that they have never seen before, lot of them do get scared."

Likewise when 7FN talked about how she thought dignity changed as children grew up, she commented:

"...smaller children, it's more to do with meeting strangers, um obviously they are not used to different people and you know they are less aware of what is going on."

The emergence of an awareness of “stranger danger” in recent years has brought to the awareness of staff, parents and children alike, a concern about who looks after the child, especially with regard to more intimate care. Roles of health professional have evolved alongside these concerns. As a male nurse working on a children’s ward, 1MN was conscious of his gender. I wondered whether this was in part a result of the media attention to the vulnerable position of children in relation to carers especially male careers and the potential of abuse:

"...For myself working with a teenage girl, I am very, very conscious that having a male involved in some areas of care, even if its taking a temperature, an axillal temperature, where it could be, if she's wearing a loose gown or something, that could be quite embarrassing to her"

6.3 Changes in the role of the children's nurse

There have been considerable changes in the way children are cared for in hospital. In particular is the greater presence of parents (usually mothers) to the extent that they are often with their child constantly. The presence of parents was much greater during the Main Study (2005) than the Pilot Study (1998; 4.2.8). In the observation notes from the Pilot Study, 10.05.98 I recorded:

*I noticed that babies got left for longer periods in their cubicles and there was more crying, as the ward was very busy. Three babies did not have parents on the ward.*
The sites for the Pilot Study and the Main Study were different and served a different population (4.2.4; 5.2.1), and this influenced whether a parent was able to be present. The ward in the Main Study had been redesigned and developed to make it appropriate for children. Ensuring the suitability of hospital facilities to fit the needs of children and their families was an expressed aim of the National Service Framework (Department of Health, 2003). A Play room devoted to the children's play had been incorporated and was central to the design of the ward. Play had been a feature of the Beauchamp ward, but had taken place in the ward areas that could have been hazardous. Nurses in both studies did not play with children and this was reinforced in the Main study by the separation of play into a separate Playroom.

The Report of the Platt Report (1959) and the Report of the Court Committee (1976) promoted the involvement of parents, putting greater emphasis on family centered care. One of the principles underlying these recommendations is described by the Audit Commission (1993, p. 9)

"Children are part of a family and dependent on their parents for physical and emotional care and support. Caring for a child means involving parents and siblings"

The National Service Framework for Children (2003, 2.2) standard for Hospital Services was an attempt to set standards for "every department and service within a hospital that delivers care to children and young people." Child-centred services tailored to their individual needs and those of their families was a key aim, with the experience of being in hospital made as "normal" as possible (Department of Health, 2003; 2.12).

In addition to increased parental presence, children nowadays are treated increasingly as Out Patients, or at home and the length of hospital stays are kept to the minimum and the throughput of patients rapid. These factors together with changes in political climate, nurse education and skill mix have all had implications for nursing. Some of the nurses reflected on these changes. Some of them had been nursing for long enough to remember the time when parents were scarce on the ward and they talked about how this had changed their role.

6.3.1 Parental presence
Pre-school children are catered for increasingly in institutional care settings, rather than
cared for mainly by their mothers. Yet the adoption of family centred care has led to
parents, caring for their child full-time in hospital. Nurses commented unanimously that
having parents stay was a good thing for the children. Nurse specialist 8FN described
what she thought it would have been like for the children in the past without their
parents:

"It must have been very traumatic for them".

The other specialist nurse, 10FN, who has three children of her own, reflected on the
increase in parental presence:

"I trained when parents weren't allowed on the ward. I have been a nurse for
thirty years. A huge step forward, it's made life much easier. I was working
with nurses who said it wasn't easy "She gets in the way, she does
everything wrong, oh she's feeding that baby again at the wrong time." If it
was my baby I wouldn't let anyone else touch it."

Recently qualified staff knew no different. Staff nurse 5FN had trained in Scotland and
had been working on the ward for six weeks at the time of interview. She said that she
had "never had a parent who had left the child, if the child is in for a couple of days".

2FN talked about what impact it would have if the parents were not allowed to stay:

"We wouldn't be able to cope with the work load, because the parents do an
awful lot of what traditionally is considered nursing care. A lot of parents are
very active in their child's care in terms of the nursing role as well as the
parenting role, so we need parents to be resident"

With the move to nursing becoming a university-based profession, student nurses are no
longer there to give hands on care in the way they were once relied upon to do, as they
now have supernumerary status. Hands-on-care has now been taken over by the
parents. 11FStN was supernumerary on the ward. From her response, it sounded as if
she would have appreciated a traditional approach. She admitted:

"I quite like it when they (parents) go because then you get, especially the
babies, you can have some time playing with them, or feeding them which is
quite nice because you don't get to do that a lot. Mums are here feeding and changing them.

In my observation notes of 13.07.05, I noted that a member of staff was sitting beside the cot of one of the children while her mother was on the phone. She was a newly appointed Health Care Assistant and was sitting reading a book to cf2054. Reading to a child seemed to be a pleasurable activity for both the Health Care Assistant and the child. I reflected how unusual it would be to see a trained member of staff doing that. I speculated that the trained nurses might no longer consider reading to a child as part of their work. So habituated they were to being constantly busy and “doing the horrible bits” (6.3.2) that, when quiet, the nurses used the lull to catch up on paperwork, or attend to their own fatigue by taking a break.

The recent trend of parents staying with their child, together with the reduced length of stay was couched in terms that made it seem favourable primarily for the child. 14MD said:

“Now we keep the children in hospital for as little as possible. In and out very quickly... Treat them partly as outpatients in that we let them go home for part of the day’ (14MD).

Undoubtedly this speedy turnover of patients had additional economic benefits, but these were not always appreciated by the parents (7.13.2). The staff too had reservations and there was a sense that the nurses had lost out in terms of a deeper and more fulfilling relationships with the children. 8FN said:

“When I was nursing (on the wards) we had many more long term patients and we got to know them much better. Often they were away from their parents. Parents weren't as welcomed around at the time, more visitors rather than staying with their children all the time. You got to know your patients much better than you do now, slower turnover, able to find out what they liked and didn't like.”

Staff suggested that as the presence of the parents had increased, so they were able to form better relationships with the parents, but at the expense of the relationship with the child. Staff nurse 9FN compared working when she was newly qualified, approximately thirty years ago, with working as a children's nurse today:
"You often don't get particularly good relationships with the child, but you might do with the parents."

There was ambivalence amongst the nurses about how parental presence affected their work. Increased parental presence meant that some of the caring activities, previously undertaken by the nurses both students and qualified nurses, was now undertaken by the resident parent. The decision making process had also been affected at a day to day level on the care and treatment of a child:

"We can't really do anything without the permission of the parents and if they don't agree, or they don't like the way things are done, then we have to listen" (9FN).

6.3.2 Doing "the horrible bits"

8FN also compared children's nursing today to when she was working on the wards:

"We spent a lot more time with the children, not just doing the horrible bits, it was mealtimes we were there feeding the children, playing with them, getting them bathed, putting them to bed. We were doing all the things the mums weren't allowed to do."

There was a strong sense that, the nurses were now left to do the "horrible bits" rather than the caring that they seemed to find more rewarding on a personal level. The fast turnover, made possible partly by the presence of parents on the ward, has altered radically the role of the nurse as described by 6FN, who had been qualified for two years:

6FN: "We're the bad guys and Mum and Dad be the comforters."
R: "What's that like for you?"
6FN: "um, what being a bad guy?"
R: "Yes."
6FN: (Laughs) "It's hard sometimes, but you know that it's in their best interests at the end of the day, to get them better and back home as soon as they, as quickly as you can."

6FN rationalized her position by putting aside her own feelings (6.12.2) and saying that it was for the "best interests" of the child.
6.3.3 Building relationships

The average stay on the ward was just forty-eight hours, and so the nurses had little
time to get to know the patients and their families. A considerable amount of paperwork
and procedures were required for each admission. 8FN commented on the amount of
paperwork the nurses were required to do:

"You've not finished writing up their likes and dislikes before they are
actually going home again. Look at all the paperwork I did and actually what
help did it give the child with being in hospital?"

As well as the fast turnover, the burden of paperwork limited the opportunities for nurses
to get to know the individual children. Moreover, taking baseline observations on a child
at admission seemed to have evolved in a way that maintained the distance of the nurse
to the child. I noted in my observation diary:

9.12.05 I am wondering how accurate oximeters are, especially on a wriggly
child. The nurse's attention is on the machine rather than on the child. As a
consequence, the limited time available, to form a relationship with the child,
is compromised by the machine taking priority.

For me, this observation became a metaphor for the change in the nurses role from the
intimacy of 'old-fashioned' taking of observations, to the distancing demands of
contemporary technology (6.13).

Staff nurse 1MN described the system for a child coming in for a routine tonsillectomy.
His description implied his dissatisfaction with the way the process was carried out:

"Comes in, in the morning and it's a rush to get them ready for surgery first
thing, even if they've had a pre-admission sort of clinic and they've come to
have a look round, not likely to have seen the same person and they come in
and it's a very daunting process, a very fast process and they go down for
the operation, especially the younger ones. They don't know what's involved
and afterwards they are in a lot of pain and very uncomfortable and just want
to go."

Experienced staff described a past era of children's nursing characterized by longer
stays of children in hospital. 9FN reminisced about some of the children whom had been
in her care many years ago:
"I can remember children by name that I looked after when I was training because of the length of stay. We would have children who would have tonsils out who were in hospital for seven days."

The opportunity to build a relationship over a protracted time was thought, by the staff, to benefit the child. 1MN who had had extensive experience working with long stay children and young people with disabilities, thought that being in hospital was:

"...a lot easier for children who are in here for prolonged periods of time or who are in and out, because they get to know people."

I wondered how much this comment was based upon the clear preference expressed by him, and some of the nurses, to care for children they knew. Staff implied that they thought children who were in for longer got better quality care. 1MN stated:

"Seeing a face you know on a regular basis can make the world of difference to the quality of care that you get, in the same way that having staff that know you improves what they are able to do for you."

Specialist nurse 8FN felt that "the 'old way' was more patient centred.

It was not just the children who the nurses thought benefited in some ways from longer stays, but the nurses themselves. The nurses generally seemed to find caring for the children they knew more rewarding and looked forward to children returning.

"Quite a few that come in as babies keep reappearing. It's nice for us as we see how they are getting on" (2FN).

A considerable component of the work nurses found rewarding was based upon a continuing relationship between them and the child. However the changing nature of the role and fast throughput of patients limited opportunities for relationships to develop and be sustained.
6.3.3.1 Time

The more senior nurses on the ward, in particular, described their busyness as something that got in the way of them carrying out their care in the way they thought they could.

“I think sometimes we explain things and go racing off and doing it and we don't stop at any stage and check whether they do really understand” (12FN).

Busyness was seen as a factor in limiting the nurse’s opportunity for getting to know and communicating with the children:

“I think sometimes we spend so much time rushing from one thing to another and get the bare minimum done and you don’t always give priority to sitting down and discussing it with people” (2FN).

2FN described her role when she was in charge of the ward:

“Me, as the nurse in charge, will go and set up the child’s antibiotics on a drip, make sure the cannula is working and I'll be on to the next person that is due antibiotics at the same time. Buzzed in and buzzed out again and not had the chance to say “How are you feeling about what’s going on?”

Busyness, in both the Pilot Study (4.2.6) and the Main Study, meant staff were elusive to others on the ward, myself included. The senior sister on the ward declined to give me an interview citing time constraints. Moreover, at our first meeting to discuss the research she made clear the burden of work she felt, as recorded in my observation diary:

18.1.05 My first meeting with the ward sister and the Matron following ethics approval. The ward sister makes a few comments “Very busy, everyone is knackered, a big ward with twice as far to walk. A lot of the dignity issues have been resolved. No handover, only half an hour”. Nurse in charge also has 4-5 patients to look after herself aside from everything else.

Busyness seemed to preclude intimacy and I speculated that busyness could also be used as a defence by staff to protect them from intimacy and from having to engage constantly with the emotions of the children and their parents (6.12.3). Holloway et al
(1998) note how time is a scarce resource for staff and this in turn allows them to take control of time in hospital. Where control has shifted from health professionals to families is in the day-to-day care and treatment of the child. Negotiation with the parent over treatment has become the norm in family centred care. The concept of family centred care has been integral to the provision of health services for the past twenty years (Corlett & Twycross, 2006). It is based upon the understanding that the family unit is a beneficial influence on the well being of the child and the input of the family is important and needs to be valued by professionals in the planning and implementation of care. This creates a triangular pattern of communication, treatment and care. It is this triangular relationship that I shall now turn.

6.4 Health Professional, parent, child triad

As I have discussed, closely linked to the changes in the role of the Children’s Nurse has been the involvement of parents in the care of their children while in hospital. The adoption of family centered care as the gold standard in caring for the child has recognized the parent(s) (and to a lesser degree the siblings) as fundamental to the existence of the child (Audit Commission, 1993; DH, 2003). Throughout the fieldwork the influence of the relationship of between the health professionals, the parents and the child was apparent. This three-way relationship can be described as a triad.

Figure 10: Relationship Triad

![Relationship Triad Diagram]

The impact of this relationship was described by one of the Paediatric Consultants:

“You’ve got to communicate with the child, you’ve got to communicate with the parents...It’s a three way dialogue” (14MD).
This triad could lead to an indirect line of communication channeled through the parent. The involvement of families in children's nursing was contrasted, by one of the junior sisters, with their distance in adult nursing:

"With adult nursing you can have a one to one with your patient, the family are on the other end of the 'phone and you refer them back to the patient to give them any info" (2FN).

Parents could act as an important conduit of information from child to health professional and back. They were able to translate what the child was expressing to the health professional as well as explain to their child what the health professional is saying. The staff looked to the parent to guide them in their communications:

"Depends on the parents, guided by the parents and the way they speak to the child" (2FN).

The ideal of three way family working was described by 7FN:

"Each family is different...they all have different needs and its sort of working with the families to try and get the best outcome for the child really."

9FN thought that care could be given more effectively, if it was centred on the family and the children benefited from having their parents there. This in turn was of benefit to the staff:

"...You can negotiate through parents. They (the children) are much more cooperative usually, much easier to deal with I think and more open to being treated actually. More compliant."

Sometimes professionals could be seduced by the ease of communication with the parents, as opposed to the child, and so the child could be left out of the conversation. I was interviewing cm11088 and his mother when his consultant and a Registrar came into the room. In my observation record 14.12.05 I noted:

*He (Consultant) talks mainly to his Mum, the two of them dominate the discussion. They talk about his (cm11088's) body......On his way out the Consultant asks cm11088 if he has any questions. 'What about my mood?' He has been feeling very low with his reducing dose of steroids.*
Thus cm11088 has to force the consultation back to his subjective experience of his illness and what was important to him at the time – his low mood.

8FN acknowledged that in that in a three-way partnership, preference could be given to the needs of the parents rather than the child:

"We look at how parents are coping with things and how their needs are met and hoping then that the parents are meeting the child's needs."

10FN commented on some of the difficulties with good communication in general:

"We aren't good at listening to what people are telling us and sometimes we think we know best."

Sometimes the needs of the family were more easily recognized by the staff and overtly addressed in preference to the child. 13MD talked about the difficulties of not exposing and maintaining dignity for babies, instead he aimed to promote dignity for the family:

"And so dignity for babies often goes out of the window, but we can maintain as much dignity as we can with the families by removing other families from the room when we are talking about their child."

Although I had been told that this was done at one of the referral hospitals to which children could go, I was not aware of this being done at the research site during my observation period.

6.4.1 Role of the parent.

There was an assumption by the health professionals, that the parents, usually mother, would act in a certain way(s) to benefit the child, that their mere presence would mean that the child is “not left on a ward...unfamiliar surroundings” (16FD).

Although more experienced staff seemed clear about what they could expect from a resident parent, 11FStN was uncertain about the role of parents on the ward:
“Do they have a role? Encouraging them to eat or drink after surgery. You don’t expect them to do anything. Some mums come and tell you when the IVs are through.”

6.4.1.1 Advocate

Some staff saw parents as acting as an advocate for their child while they were in hospital: “Their sort of advocate” (6FN). Consultant 13MD described parents as there to “support their child and act as their advocate.” 14MD used the term advocate as well as he described the role of the parent as “the child’s guardian and watchdog.”

However, some parents were less able than others to act as an advocate, or be at the side of their child constantly for a variety of reasons (7.5.2.1). 15FD recognized the difficulties some parents experienced, she said:

"I think in hospital situations it is quite hard for parents, 'cos they don't know, they kind of, in some ways, are patients themselves. There are some parents that are very capable of standing up for their children and there are some that won't and there will be some that, you know, for instance can't, can't hack being in there when their child is having a blood test because it's actually too awful for them."

Specialist Nurse 10FN also acknowledged the challenges faced by parents:

“If you put parents into an environment where they are completely out of their depth it’s very difficult. Like going into a board room meeting.”

Likewise 8FN talked about the guilt experienced by mothers when they could not be with their child all the time, for example those with other children:

“Being torn between being at home with their children and "should I be here with the baby?" They feel guilty if they go and have a cup of tea or go and have lunch or something.”

Among the nurses there were critics of family centered care in the context of the hospital ward (10FN) and the lack of support for parents in their role in this triad:
"We are so busy trying to get them to do this family centered care, that we are no good at thinking of the parents' role in protecting children's dignity. What we are actually saying is 'Well, get on with it.'"

On occasion, the reliance on parents to explain and prepare their child lead to conflict, 2FN gave this example:

"Harder when the parent is trying to withhold information from their child and you are going to give them pre-op medication ... and the parent comes in and says "I haven't told them why they are coming into hospital" and that is really hard and they need to prepare their child."

12FN acknowledged that knowing their role was particularly difficult for new parents, or for those who were new to the hospital. Having to get used to the idea of being the 'parent of a sick child' could make speaking up on behalf of their child more difficult:

"New parents don't understand what their role is... so it's quite a strong parent who is a new admission to the ward, who turns round and says 'no, you're not going to do that' and they are often labeled as the difficult one" (12FN).

Parents had to risk being labeled as 'difficult' if they were to get their views, or those of their child, heard (7.5.3.1).

6.4.1.2 Reacting in unexpected ways.

Staff recognized that some parents did not always act in the way that was expected of them and reacted in ways that were unexpected. 14MD described the different reactions of parents:

"In an alien situation... people react very differently in hospital", some parents who are otherwise "very rational, go to pieces in a hospital situation" and "Amazingly can be verbally abusive to the nursing staff and aggressive towards the medical staff."

He described other parents who were:

"... very sensible, very calm, very passive, understanding, helpful and calm him (a patient) down when he is worried."
It was interesting that the consultant listed "passive" as a useful quality in negotiating about care (7.5.2.2).

6.4.1.3 Parenting styles

Some staff were upset by the way parents spoke to their children, finding them very aggressive and at odds with their own styles of parenting or caring. 2FN said:

"Some seem to have aggressive relationships with their children, some people swear in front of their children, quite you know 'When your Dad comes you're going to get a smack if you don't do this.'"

This could affect the relationship between family and staff. 1MN also spoke about parenting styles that he thought ran counter to his own values:

"There are various lines, when you are getting across into the areas of neglect, abuse and similar things. That's a different kettle of fish and I'm not saying it's acceptable, because I don't think it is. However, just because someone parents differently to how I might appreciate, it might be frustrating at times, I might not agree with it, but I don't feel it's my place to make judgments on them."

Thus staff hesitated to be judgmental about parenting styles in a similar way to the parents hesitating to speak up for their child for fear that they may be labeled as trouble or "difficult" (7.5.3.1). It also meant that both staff and parents, at times, remained passive rather than challenging ways of dealing with children they thought to be inappropriate (7.5.2.2).

6.4.1.4 Presence at painful procedures.

Despite being present for almost all of the time, parents were often not present when their child underwent a painful procedure, such as a lumbar puncture, or even cannulation. When I asked 7FN about this she said:

"Cannulation most people stay, for a lumbar puncture, most people go. They are advised, but often by the doctors that it is not a nice procedure to watch, but it's up to you, but we would probably advise you not to."
In some cases a nurse might deputize for a mother if they are unable to be with the child. Consultant 15FD explained how she undertook procedures on babies:

“If their mum is able to cope with it, then you know let the mum cuddle them whilst you’re doing it and, but if Mum, there may be situations where Mum is not able to do that and that makes things worse. So in that situation get a nurse, or somebody, to give the baby a cuddle and as soon as it’s over...try to minimize it.”

The needs of everyone involved seemed to be taken into consideration in determining who should stay at a painful procedure, all but the child. Even the choice of who cuddled a child seemed based upon who so ever was available at the time, rather than someone who had a established a close nurturing relationship with the child. 14MD said that parental presence depended on the procedure, the parent, and who was doing the procedure:

“Some want to stay and there are those who would not like to see their child put through anything that would upset them.”

The professional undertaking the procedure assumed control over who was present:

“Junior doctors may feel embarrassed or worried about the parent being there because the parent will know it’s their first time they’ve done something, because you are actually explaining how you would do it” (14MD).

Experienced nurse 9FN described her difficulty in having the parents present during a lumbar puncture:

“They don’t particularly like being in on those, particularly small babies. I think they find that very difficult. Because it’s not a nice procedure to do in front of parents and I don’t like, I hate, I hate doing them in front of parents because I don’t actually like the process of actually having to hold the baby because of the position you have to hold them in, it looks barbaric.”

In this case, the experienced nurse 9FN, did not like holding the baby for a lumbar puncture. This was made worse for her having the parent there as witness, possibly judging her as cruel in the way she held the baby. I wondered if to be seen deliberately hurting their child would in some way damage a belief in the caring kind nature of the
nurse. Thus these procedures were done in private. By being present at a painful procedure, parents would not be able to escape the fact that they actively condoned the procedure. Although responsible for so much of the care of their child in hospital they were able to abdicate responsibility when pain was inflicted and were able to hand it back to the professionals.

I asked 16FD what it was like for her having to perform painful procedures on children:

“It’s never very nice, but it depends who you are working with and how they interact with the nurses and things and the way their parents... Sometimes it’s better for the parents not to be with them, sometimes its much better for the parents to be with them, it depends on the individual and the circumstances... It depends on the age of the patient, sometimes they are more distressed without their parents there. Sometimes the parents are much more distressed when they are there. Yeah, the parents are more distressed than the child. Little babies having bloods done is not very nice for the parents to watch.”

When a procedure was undertaken on a child, parental presence seemed to depend upon the preferences of the doctor and those involved in undertaking the procedure followed then by parental choice. The needs of the child did not predominate as a deciding factor, the needs of the doctor and the parent took priority.

6.5 The construction of children by the staff

The literature review revealed the discourse concerning the meaning of ‘the child’, and children, and their construction in society. The staff interviews provided insight into how the child and children are conceptualized and constructed by the staff in hospital

6.5.1 Long term and acute stay.

One of the ways staff discriminated between children was length of stay: whether the child was there for an acute, time limited admission, or whether they were returning patients, or patients that had been in for a longer time. This factor had important implications for the way the staff thought of the children and their families and it also had important implications for the way the child was managed during their stay.

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In particular the nurses seem to value the closer the relationships they are able to build with children who stay longer or who are in more frequently (6.3.3). This difference was explained by 8FN:

"Long term patients, they are known by all the staff on the ward especially the nursing staff. They become more of a friend. 'Oh it's ...coming in today make sure this is sorted out before he gets here.' Other people come in get processed and hopefully go back home and people don't get into that same sort of relationship."

2FN too described her appreciation of being able to build up good relationships with the children and their families who were in hospital for longer, or more frequently:

"A large percentage come in, stay one night and never see again, but then on the flip side there are a large proportion of the families you do build up good relationships with and get quite close to."

6.5.1.1 Reciprocity

Responses from the staff indicated that they appreciated the relationships they are able to develop with the children who are in for longer or who have more frequent admissions. Staff indicated that they thought the parents were also pleased to see them again. 2FN hinted at a reciprocity of feeling about meeting up again when she said:

"It's nice for the parents."

Coming back into hospital was thought likely to be a positive experience for children, and particularly for their parents. 2FN stated:

"Quite a few that come in as babies and keep reappearing, nice for us as we see how they are getting on and nice for the parents if they have had a good experience early on."

Consultant 13MD echoed this sentiment:

"Those that have been coming backwards and forwards very often, they know everybody, they know the staff, they know many of the families that come backwards and forwards regularly anyway and therefore for them it's a
social gathering, rather than a frightening or worrying or exposing experience."

Staff enjoyed the relationships they were able to build up with the children and families who stayed longer or returned frequently. Staff assumed that their feelings were reciprocated by the children and their families. However, 12FN was more cautious in her analysis of what it was like for the longer stay children:

"People may become complacent with children who are in and out and may assume they are happy with things and maybe don't talk to them or discuss things with them. Maybe over a period of time you realize that the child's needs have changed."

As I have described, most of the children on the ward were in and out very quickly. Nevertheless some staff expressed dissatisfaction in the way they were dealt with based on a sense of not getting to know them:

"We're not really able to provide for them to the best of our abilities and to meet all our needs because we just don't know them well enough" (IMN).

12FN concurred and, referring to the child who comes in for a short stay, she said:

"(We) may make assumptions about a child who comes in for a short admission because you don't know the child very well, you don't know the family very well."

Although the children were kept in hospital for a shorter time, staff felt that this could undermine the quality of their care as the staff did not get to know them as individuals. They intimated that the children did not benefit from a close relationship with the staff. I speculate that this could also be a projection\(^5\) of the staff, of their own feelings of dissatisfaction at not being able to form a closer relationship with children admitted for a short stay and more generally.

6.5.2 Gender

\(^5\) Projection is a term used in psychoanalytic theory. Projection describes the way in which we can ascribe to another a feeling that is (also) our own, but which we apparently do not acknowledge as ours (Jacobs, 1988). This is an example of using psychoanalytic principle as a "tool of analysis" to further my understanding of meaning (Theodosius, 2006; 5.4.2.1).
The Children's ward had a range of ages from between 0 and 16 years of age. It was a mixed ward, with more boys than girls as In Patients. 13MD commented on having mixed sex wards in the context of maintaining dignity:

"We are pretty bad at maintaining the dignity of children in hospital because things like mixed wards in adults are in theory a thing of the past, but not in children."

There seemed greater awareness amongst the staff of the self-consciousness girls felt about being in hospital and their bodies. For example, they thought that girls would rather be treated by someone of their own sex:

"If a girl is coming in with heavy bleeding for a period, she would be quite embarrassed. She would not necessarily want a male doctor talking to her" (5FN).

16FD described an incident when a girl requested that she, as a female doctor, perform the necessary ECG (echocardiogram) rather than a male doctor. She had not had any experiences of a boy requesting a male doctor in a similar way.

None of the staff commented on female nurses and doctors caring for young male patients. The only exception was when one member of staff, 8FN, talked of her son's experience, from her perspective as a parent. He was admitted with a painful groin aged fourteen:

"He found it horrific that it was a very nice SHO, a very attractive girl who came to see him."

I wondered whether it was easier for the mainly female staff to acknowledge the sexuality of the adolescent girls, but less so the adolescent boys. Black (2005, p.35) in her discussion of sexuality and disability states that:

"sexuality is poorly understood by nurses, who are reluctant to address client needs, particularly of children and young people."

In her ethnographic study of how nurses provide care, Lawler (1991) suggests that sexuality is difficult to discuss since it is close to the margins of respectability. Nurses,
Lawler argues, learn early in their careers to manage their own embarrassment. Nurses underplay the significance of an event both verbally and in affect through "minifisms". This in turn gives patients permission to not be embarrassed. The literature pertaining to nurses and the sexuality of adolescent boys in their care is scant, with studies focused upon the particular needs of children and young people with disabilities (Aylott, 1999; Black, 2005). I suggest that that female staff were threatened by the sexuality of teenage boys as patients and ignoring sexuality had become a way of dealing with it on a children's ward. This is an area that warrants further research and exploration.

6.5.3 Something to be observed

Christensen (1998) describes the way studies of childhood health and illness emphasize the "child as a subject acted upon by others." Likewise during the research, staff spoke in a way about the children that seemed to render them, not as not active agents, but passive recipients of observation, measurement, treatment and care. 14MD commented that it:

"Makes me annoyed when medical students use the word 'It' -- it's a person, do you mean him? Her? Has 'It' got a name? I pick them up on that..."

Thus the child's body became the focus of medical speculation and the embodied, experiencing, participating child was left in its shadow:

"You have to accept that children have to be observed and one way that I am keen to do is to try and observe the children as unobtrusively as possible and remotely sense them...without having to keep interfering with them, so that they can carry on with their day to day activities" (13MD)

In the quote above, the consultant conveys a sense of the child as something to be observed, rather than to interact with, during their hospitalization.

6.5.4 Someone's possession

A similar theme was the child as "belonging" to another. It seemed that sometimes staff, particularly those who had had children of their own, found it easier to identify and empathize with the parent of the child rather than the child. It was as if the child was
seen as a possession of another and that their value was as just that, a valued possession of another.

"At the end of the day there's somebody's baby or child at the bottom of that resus..." (12FN).

The importance of a child because of his or her value to another resonates with the construct of favourite from the Pilot work (4.2.12). Where, in the absence of the mother, it seemed the staff had assumed ownership of the child, Lester, as their treasured "favourite" on the ward.

A child's value and the parent's ability to articulate this has important repercussions in their care. For young children, their value to their parents will influence the decisions made for treatment and care. This is made explicit in the discussion of the ethical issues surrounding critical care decisions in fetal and neonatal medicine (Nuffield Council of Bioethics, 2006). This report outlines the how best decisions relating to the care of the fetus and mother before birth should be made. It gives guidance on the treatment of premature and very ill babies, including whether to resuscitate a newborn baby and whether to continue invasive intensive care or substitute palliative care. The report encourages a consensus of opinion but states:

"Parents are considered to have the moral authority to make decisions in their child's best interests in all the circumstances of life, though not as if they owned them."

Although parents do not own their child, therefore, they have a considerable and valid say in how best their lives are to be managed. In "Further recommendations" the report contrasts the dilemmas of heroic interventions for premature infants with how to handle late abortions. The report identifies the need for a code of practice to give clarity to such situations (para 9.10). I return to the issue of ownership when I discuss how parents described the child as "my child" (7.6.1).

6.5.5 Age

Chronological age is an important and defining measure of children. From considering age, a whole range of predictors emerge including likely size, cognitive ability, verbal
ability, the incidence and prognosis of a variety of medical conditions, appropriate play things and even food choices. Following on from this, consideration of age in hospital was a determining factor for care and treatment options. For example, the children were on the Children's Ward, being treated by specialist paediatric trained staff, by virtue of the fact that they were sixteen years old or younger. Age and its associated characteristics was an important factor when constructing what was 'normal', anything other was treated with interest and speculation.

The staff respondents referred to age as one of the ways they pitched the way they communicated with the children, for example (6FN) said in her response to what she thinks was really important for children in hospital:

"...speaking to them at the level for their age group."

Similarly, 7FN, choosing the term “developmental age” in preference to chronological age, stated:

"I think communicating with children is the most essential thing, and obviously depending on their developmental age will depend on how you will communicate with them".

With the very fast throughput of children, assessing developmental age was very difficult. One member of staff reflected upon her experience as a mother of a toddler in hospital and questioned the use of age alone as a predictor for appropriate care planning, when she said:

"We sometimes group children together of a certain age group. I think that is wrong now and it’s looking at that child and parent as individual. When busy you just see them as a 3 year old, you don’t look further than that" (12FN).

Staff spoke about the age of the child in the broader context of dignity. In some cases staff suggested that it was easier to overlook the dignity of the younger children and babies particularly in preference to medical need.1MN described how in Special Care or Neonatal Intensive Care:
"The baby being so unwell and maybe it not always being in its best interests to be held, or to sort of allow bonding between parents...Their medical need or their physiological need is prioritized over their emotional or psychological."

The ward had a bay that was the designated “Adolescent Bay”, but at the time of the study this was not functioning as such due to lack of money for staff. Adolescents found themselves in beds next to toddlers, especially in the High Dependency Bay. When asked what she thought was really important for children in hospital, 10FN replied:

“If you are fourteen, you don’t end up next to a two year old. It’s really quite offensive as a fourteen year old. I get that impression from most kids I’ve looked after. The thing that really hassles them is this idea that, ‘They think I am the same age as them.’”

She thought that children, in particular adolescents wanted their age acknowledged and to be differentiated from the younger children.

6.5.6 Children with disabilities

Reliance on assessment by age was less useful when a child with learning difficulties was admitted. There seemed to be a subtle reticence about caring for children with special learning needs. The staff seemed particularly dependent upon the parent or main carer who was resident with the child:

“Some children are more difficult to deal with than others, particularly children with special needs. We couldn’t cope without the parents, we really couldn’t you know, they are invaluable” (9FN).

Despite not having information about the medical conditions of a child, I was told when a child had a learning difficulty. It was almost as if the nurses lay claim to medical diagnoses, but a specific learning difficulty was outside their remit and so could be made known. Generally I was encouraged not to talk to these children and their families by the nursing and play staff. For example I was told by that the parents of cm6024 were “not keen on letting you in” (observation record 4.05.05) and a boy with Asperger’s syndrome “did not want to be disturbed” (observation record 7.10.05). Although I experienced some reluctance to take part in a taped interview by some of the parents of children with special needs (7.10.4), I found them very welcoming and willing to talk informally.
wondered whether the caution to me about approaching these children was a reflection of the staff's reticence at approaching these children themselves.

6.5.7 Future oriented

The child, in the literature (2.3.2), is seen with his, or her, future in mind rather than their experience of the here and now. There was some evidence of thinking about the children in this way when the staff rationalized some of the treatment that was given to the children:

"It's hard because this child needs this LP (lumbar puncture), or this child needs his cannula in because they are sick and need their treatment, but to a small baby that you can't explain 'I'm doing this because it's going to make you better in the long run', somebody that you can't have that discussion with, you've got to restrain them and do it really" (2FN).

Some of the procedures undertaken were explicitly for the future interest of the child (James and Prout, 1997: 2.3.2). Such procedures included jaw realignments and surgery and treatment of congenital dislocation of the hip.

In this first part of Chapter Six, I have described the context of the ward from the perspectives of the staff. I have discussed the environment and the work of the staff to contain anxiety by normalising the strange and managing public and private domains. I have described how the nurses spoke about their role and experienced nurses offered insights into how this had changed over the years. Since parental presence had become common place nurses had been displaced from day to day caring activities. Family centred care had resulted in a triadic relationship between the child, parent and staff member.

The staff constructed the children in a variety of ways. Staff differentiated between children attending for short stays and longer term. Children were mixed by gender on the ward with the staff expressing awareness of the embarrassment girls might feel. Children were in hospital to "be observed" rather than acknowledged as active agents in their health care. The value of children to their parents was understood. The age of a child was an important predictor for the way children were communicated with and treated. Where children fell outside of physical or psychological norms staff were more
hesitant and reliant on the knowledge of the parent in establishing care needs. I will now continue on to explore the meaning of dignity as understood by the staff participants working in the total environment of the Children's Ward, before drawing the two sections together in a summary of this chapter (6.14).

Part II  The Meaning of Dignity for the staff

6.6 What does dignity mean for staff on the children's ward?

In the second section of this chapter I discuss what the notion of dignity means as described by staff participants. I explore how they consider dignity to be pertinent to children in their care. I look at how the promotion of dignity is played out through the behaviours of the staff.

A review of the literature demonstrated that a number of different understandings prevail at both a theoretical and practical level, as evidenced in the philosophical, medico-nursing texts and empirical studies. I was interested to explore both what dignity meant to the staff working on the children's ward generally and, in particular, in relation to the children on the ward. At the level of the institution, dignity was included in the Hospital Trust's second value statement: "We treat everyone with respect and dignity."

As outlined in the Methodology Section, I began each interview by asking a range of open-ended questions to gain some background about the respondent, I then asked "What do you understand by the term dignity?" Respondents found it difficult, on the whole, to tell me what they understood by the term dignity. Some respondents found it easier to put their understanding of dignity into words by putting dignity in context, and gave examples direct from the ward. Much of what they understood by dignity was revealed as they talked during the course of the interview.

6.6.1 Definitions of dignity

Staff defined dignity in a range of ways that demonstrated the subtle differences of meaning especially when they considered children. Meanings of dignity were difficult for staff to define and to extrapolate for me as the researcher. Nevertheless, I have
clustered their responses around five main themes: principle, protection, interactional and promotion. Of course many respondents used a combination of these themes during our discussions, but each tended to have a bias towards one way of describing dignity. Examples below have been chosen for their typicality of response.

6.6.1.1 Principle

An explanation based upon a principle was often referred to as a ‘human right’ to dignity The doctors were most likely to respond to my question “What do you understand by the term dignity?” with a definition using a principle. For example:

“Dignity, I think is a right that people have to being cared for in a way that is commensurate with their maintaining their own status in life, so that they aren’t embarrassed or exposed in any way either visually or verbally to anybody else” (13MD).

This definition is not easily applied to children, as children have a particular status in life dependent upon them being children (2.3.2). Other respondents gave a rights based response such as:

“Dignity is a fundamental human right like food and warmth and shelter and people are entitled to dignity, which is that they should not be placed in situations where they are humiliated or subject to torment, torture” (14MD).

Definitions from both consultants included references to what dignity was not:

“...so that they aren’t embarrassed or exposed in any way either visually or verbally to anybody else” (13MD).

And:

“they should not be placed in situations where they are humiliated or subject to torment, torture” (14MD).

6.6.1.2 Protection

Most of the nurses explained dignity through operationalizing dignity and explaining the concept in terms of how they would ‘do’ dignity. It was as if they assumed responsibility
for the dignity of the child through their actions. They suggested ways of defending
dignity that emphasized the protection from eyes and ears of others by ensuring privacy
and confidentiality. For some respondents (nurses) the two terms: privacy and dignity
were used interchangeably. This was a reflection of my findings from previous pilot work
(4.2.10) and the medico-nursing literature (2.2.4). In the Pilot Study I had felt frustrated
by the apparent attention to privacy and the associated isolation overriding other needs
of children (4.2.10). I noted my disappointment at the mechanistic interpretation of
dignity and seeming to reduce dignity to pulling curtains. This was also evident in the
Main Study. For example, one student nurse responded in her answer to what she
understood by dignity, by explaining how she would protect and maintain dignity:

"Like privacy and confidentiality. If changing the child that had wet the bed
and keeping the covers over" (11FStN).

Privacy was linked directly by the nurses to dignity:

"A lot around privacy, privacy and dignity are interlinked" (2FN).

The more junior nurses, in particular, equated dignity to privacy:

"It's to do with privacy, giving them privacy as much as you can" (7FN).

and:

"Protecting people's privacy and treating them respectfully. The due respect
that you would expect to be treated with yourself" (5FN).

Despite declining to be interviewed herself the senior sister asked me, on more than one
occasion how my study on "Privacy and Dignity" was going as if she held the two
concepts in juxtaposition.

6.6.1.3 Interactional

Other members of staff related at a more personal level to my question. They
emphasized the interactional and social nature of dignity and their part in understanding
the perspective of the patient. For example 4FP gave this response:
"I think it encompasses privacy and some awareness of what the person must be going through that you are treating...keeping them isolated from people watching them, looking at them, being aware verbally and that what's going on – confidentiality."

Another understanding of dignity as essentially interactional came from 1MN:

"Dignity for me can be taken in different ways. I think it is a very personal issue, because I think everyone has their own interpretation of dignity, so my understanding is always to try and empathise with what someone else's appreciation of dignity is....they are in control of exactly what that person's doing and that their privacy is maintained at a level they are comfortable with....maintaining my own sense of personal will and choice...is about feeling in control and feeling respected."

And from 8FN:

"How somebody feels about something. How to die with dignity? Their wishes about how they would like things to be are respected, treated the same as if they were fit and well and not just calling them 'Gran' because she is an old person."

It was interesting that respondents could describe dignity more readily using the analogy of an older person, even though the discussion, and their working life was about children. The association of the vulnerability of older people and dignity is evidenced by the literature (2.2.5.1). The link between children's vulnerability and dignity is not.

15FD responded in the context of herself as a doctor when she commented:

"I think it's about respecting the rights of the individual that you are seeing. Things like thinking before you do things to them."

This doctor offered an understanding of dignity that incorporated the reactions of the other. She moderated her action in anticipation of the child's response.

6.6.1.4 Promotion

Other staff emphasized the promotion of dignity through respect and the empowerment of individuals, giving them control. 10FN said:
"Giving people respect for who they are and protecting people from being exposed in situations that would make them feel vulnerable. Allowing people to participate in their care and understand what is happening to them."

Some staff emphasized the individual child and their needs and choices when discussing dignity:

"Looking at how the child is treated, whether their wishes are respected, listening to the child…not sure what a definition of dignity would be …treating them as an individual" (12FN).

"Respecting people’s wishes, privacy, respecting what people want in terms of their beliefs and attitudes and trying to accommodate them within the environment" (2FN).

"In a general sense, I guess it’s (dignity) is connected with respect, to feel comfortable that one is respected and that one’s own wishes are respected."

She goes on to say about children and dignity:

"Respecting children’s privacy, that they are not expected to do things that are unacceptable to them, that they are given the chance to have their say" (9FN).

Several staff respondents described dignity in a number of ways within their definition, but nonetheless tends towards an operationalising approach to explaining dignity:

"Dignity, I suppose it all runs in with dignity, privacy and respect. …if they have their privacy so they are not downgraded in any way and sort of empowered to be themselves and given choices that they can speak for themselves and give them dignity as a person" (6FN).

As well as demonstrating respect and empowering patients, promoting dignity was also linked with being free from the scrutiny of others. This is a theme I return to later (6.10).

6.6.2 Theories of dignity

During the course of their interview, some of the respondents demonstrated a theory about what and how dignity came to be. Some of the questions were more likely to elicit
this information without asking it directly. For example, as part of the interview schedule I asked the respondent whether they thought dignity changed as one grows up. This led to a variety of responses including how children came to have dignity. Some respondents said that dignity was something learned from their parents, others said that it was to do with life experiences or age related. Some responded in a way that suggested they considered dignity as something to be done or given, others considered dignity to be inherent and non-changing.

6.6.2.1 Developing dignity

Some respondents thought that dignity developed as a child matured and this called for different care practices:

"Yes, nappy changes are OK in public when you are 18 months old but you wouldn’t expect someone of 15 to go to the loo in public. As you get older there is an expectation that people will treat you differently" (8FN).

Teenagers were thought to be a group for whom dignity was particularly important:

"I suppose what comprises dignity, so a teenager or an adult would not want to expose certain parts of themselves, perhaps a teenager even less than an adult" (15FD).

1MN reflected on how his own sense of dignity had changed:

"I think people become more aware of their own sense of dignity and similarly my appreciation of my own dignity and someone else’s has changed."

5FN too thought that dignity changed as one grew up and became more aware of the attentions of others. This respondent made a direct link between body maturation and a greater expectation for dignity:

"You expect it more the older you get...The older you get the more aware you are that people are listening in...Plus the older you get, the different illness or syndromes, they change with age, so if a girl is coming in with heavy bleeding for period, she would be quite embarrassed. She would not necessarily want a male doctor talking to her" (5FN).
A similar explanation was offered by 7FN:

"At different ages children require different types of dignity."

She goes on to explain that children become more aware of themselves as they grow older. 13MD was also of this opinion:

"I think children are more aware of themselves and their appearance and become more shy as opposed to more afraid (as they grow older) and would become more upset if they were being treated without dignity."

The responses above reflect the view that self-awareness increases as a child grows towards adulthood. Children become more aware of their bodies and the attention of others. Adolescence was frequently cited as a time when self-awareness was heightened.

6.6.2.2 Learning dignity

Some respondents commented that dignity was something that was learned from their parents and social environments:

"Attitudes towards dignity change as you grow up and develop. It must come from their parents and their families and their attitudes and their experiences" (2FN).

"It varies, can be affected by the child's family, their life history and what has happened to them: whether they have had repeated hospitalizations, whether they have any experience of hospital themselves or someone in their family" (12FN).

The following responses from doctors emphasize a passivity of the child in this process:

"Younger children are less aware of dignity, the younger children aren’t so worried about it" (16FD).

This doctor continued:

"They will learn a lot from their parents. So how they see dignity and how they respond to dignity and protect their own dignity, the children will learn
from them and when they are younger and under the control of parents, then what it’s what they do will be based on what the parents think” (16FD).

Similarly, another doctor, 13MD said:

"I don’t think babies possess a sense of dignity, I think it’s something their parents will hand down to them and therefore the reactions of the family in relation to the baby are important."

14MD suggested that one’s perception of dignity changes:

“People deserve to be treated with respect but your definition of respect and dignity will change as you get older.”

The explanations above suggest a sense of dignity has to be learned primarily from their parents, but also from the experiences of the child. Babies were not thought to possess a sense of dignity in the same way as adults:

“Depends very much on the age of the child. When does a child become a person in terms of their dignity? I suppose one could argue that babies are subjected to indignities every day of their life by having their nappies changed by being basically treated in terms of having their every need attended to” (14MD).

6.6.2.3 Dignity as a possession

It seemed from the responses of staff that dignity was something that could be given, as in the quotes above, but also something that could be taken away. 10FN spoke about overriding the wishes of children when undertaking a procedure thought to be in their best interest (6.9.2). She alluded to dignity as if it were a possession:

“It can’t be in their best interests, if they are not prepared to participate in it themselves, that’s dignity, that’s stealing your dignity.”

Similarly another specialist nurse (8FN) described difficult cannulations on babies and the impact on their dignity:
“Often they will have two or three goes because there isn’t another person around to do it. I think then that person’s dignity is taken away because they are attacking their person and not getting anywhere.”

The quotes from the nurses above suggest a meaning of dignity as something that can be taken away, whether or not the individual is aware.

6.7 Intrinsic dignity

In our discussions, the concept of dignity was quite illusive. “Does anyone actually know what it means?” said 2FN exasperated at the end of the interview. It seemed that respondents, as they spoke, seemed to grasp their meaning of dignity, or at least part of it, and then it slipped away again. Some staff differentiated between perceptions of dignity and dignity as inherent to all people, whether they were aware of it or not. During the analysis, I found it useful to categorize these as “extrinsic” and “intrinsic” dignity and this reflected the division expressed in the literature and discussed in the Literature Review (2.2).

The following three quotes are from staff who thought that dignity, at least in part, was intrinsic and unchanging in all people. From their descriptions one can identify the dilemma of distinguishing between having dignity, being aware of dignity and being treated ‘as if’ one had dignity.

“I think your perception of it (dignity) changes as you become older, more aware, but no I don’t think dignity should change...it should be the same whether they are tiny or whether they are older” (4FP).

In terms of whether dignity changes 9FN said:

“I think probably in the person’s concept, but I think in my role as a nurse, no. I think it’s exactly the same.”

Thus irrespective of the awareness of the child in terms of their dignity, in their roles as health professionals, all patients should be treated the same, as if they had dignity (7.7.3.4). 1MN described how he used these values to influence the way he worked as a nurse:
“It’s about showing them a respect that they deserve and that they have a right to regardless of their age, gender or any other particular issues. Again as to how much that’s appreciated or understood by them is very debatable.”

10FN, in her description of dignity identified two aspects of dignity, analogous to extrinsic and intrinsic dignity that she refers to as “bodily dignity” and a more enduring “intellectual dignity”:

“So people do have different stages of dignity if you are talking about bodily dignity. If you are talking about intellectual dignity it probably doesn’t change.”

She suggested that children have a sense of dignity from a young age:

“I think people have an idea of what they have a right to keep to themselves at quite an early age” (10FN).

### 6.7.1 Relative dignity

During the analysis a sub theme of intrinsic dignity became apparent and related to babies and very young children. It is a sub theme that prevailed throughout the analysis, that of babies and young children having dignity ‘relative’ to an adult. I return to this theme when I explore the theme of “babies are less human” (6.13.1). 15FN questioned at what point are people thought to have dignity. She talked about the unborn child and in so doing, touched upon how dignity of one could be denied in favour of another, a relative dignity:

“Do we give unborn babies any dignity at all? I mean we kill them off for having various abnormalities, people perceive as abnormalities."

The wider perspective of how dignity is afforded to children mirrors the microcosm of the ward. Poverty, social structures and accessibility of resources shape the experiences of children. 15FD made this point when she reflected on her experiences in an impoverished part of India:

“It depends where you are in the world doesn’t it. If you are in India they have no dignity whatsoever. Women with pre-eclampsia are tied, on beds, to fit on the beds and tied down so they can’t fall off. There are several in the
beds sometimes and it's that or the village for those who can't afford to pay. So some of that is about resources and ideals and what can be and what can't and society has to decide what they are prepared to fund and what they are not."

She continued:

"They (children) are at the bottom of the pack in those other countries."

Disparities in the care of children are not limited to international comparisons. Inequity of provision of neonatal intensive care across the UK has been highlighted together with the need to provide national guidance on resource allocation to achieve efficiency and equity (Nuffield Council on Bioethics, 2006).

From exploring the words of the staff, I will now proceed to integrate what they had to say with my observations of their behaviours on the ward and the way dignity was enacted.

6.8 The Body

From the literature review (2.2.6), pilot work and discussions with the staff and the nurses in particular, it was evident that the meaning of the body was central to the meaning of dignity. This may have been a reflection of the way nursing has been described as an occupation being centrally concerned with the care of other people's bodies (Lawler 1991). Of all their activities relating to the care, treatment and management of bodies, bodily exposure was thought, in particular, to threaten dignity.

6.8.1 Boundaries

The body of the individual is contained within the skin. The self is separated in this way from others. In hospital, the children were separated from one another on their beds. Their bed and bed space in the bays was defined by the curtains that formed a secondary layer between the body of one child and another. The children ate at their beds and spent most of their day in their bed space with their parent.
The body of the child, estranged from the child embodied, held the 'clinical gaze' (Foucault, 1973). The boundaries of the child's body were challenged and breached in a variety of ways in hospital. The integrity of the child's body was violated, in the child's best interests (6.9.1.4), in a variety of ways; the administration of drugs for example was through the oral, naso-gastric, rectal or intravenous route. It could be difficult to see just where the child's body ended. Physical extensions of a body's boundary included drains and drainage bags.

During an interview with cm11080, (14.12.05), his consultant came in to see him. I was interested by the easy handling and talking about the drainage bags by the mother and consultant of the sick child while I was present. I found myself wondering to whom these bags belonged. Were they part of the boy's body? It was apparent that they were an extension, as I could see his bodily fluids in them. The consultant asked:

"How much is coming from the drains?"

Mum jumped forward and got hold of the two drainage bags draining from the boy's bowel:

"Well have a look...not much, good, that's about 10 mls, if that."

The boy looked at me and smiled gently, was he embarrassed with me there? He seemed uncomfortable with this examination of the faecal contents of his drainage bag. Both consultant and his mother, in this instance, assumed the right to take and handle the bags as if they were separate from the boy, even though they contained something that would otherwise have elicited social embarrassment and were emanating from his body.

This scene raised an interesting question about the meanings of physical extensions to the body boundary of the child, for the child themselves, their parents and the staff. Drains and other devices such as intravenous cannulae, urinary catheters and naso-gastric tubes constituted disturbances of the body's boundaries. They were 'in-between' self and other and were common place during hospitalization. The removal of the intravenous catheter marked the end of the need for invasive medical treatment and symbolized imminent discharge home.
A sense of the importance of boundaries of children was expressed by some of the staff. 9FN talked about herself as a child and her recognition that body boundaries and dignity are linked:

"As a child, a young child, I don't think I would even think of the word dignity, but I think I would know when it was being invaded, that as certainly as people get older and certainly as I have got older, I have realized where dignity comes in and where people have overstepped my boundary."

As well as actual boundaries such as skin, the staff showed an awareness of virtual boundaries, as if the child had a space around her or him that constituted another boundary. The importance of the body privacy and the private space is conferred by other empirical research, in particular Walsh and Kowanko (2002). Staff in this study were conscious not to disrespect these virtual boundaries. For example, 7FN talked of:

"Stepping away when patients want just a bit of privacy when you know all the nurses are crowding in".

1MN talked about not “diving in” as if aware of a physical boundary or space, the penetration of which, could be perceived as invasive.

The closer physical relationship of children to their parents was recognized, particularly the connectedness to the mother, or other important “close person” (2FN) (7.8.3). Physical space between boundaries of children was less with parents who slept within the bounded bed space of their child. In the pilot site, the sleeping arrangements on the ward were more cramped with sleeping parents separated only by the thickness of the curtain in some cases. It was unavoidable that the content of what was normally kept within the boundary of the family, slipped out in the form of auditory exposures such as overheard discussions and conversations.

6.8.2 Exposure and “covering up”

Staff were concerned about bodily exposure and potential loss of dignity. For many staff bodily exposure and the potential for embarrassment lay at the heart of maintaining and promoting dignity. They described times when they worked to keep the bodies of
children covered. 4FP talked about re-plastering a child who was in a hip spica and who had to have her nappy removed for the procedure. 4FP was uncomfortable at having to expose the child’s bottom for the medical team to check on her, even though she thought the child was unaffected and not embarrassed:

“A consultant and registrar had to come in because I was worried about the soiling of her plaster, you know and the child was on her tummy. She is too young to be fully aware, but the whole dignity of that isn’t particularly...you know bringing people in, but there was nothing we could do, they had to see that area, so in-between times we had it covered with a nappy.”

Covering up and obscuring from the eyes of others (6.10.2) was seen as an important part of maintaining and preserving dignity.

6.8.2.1 Imagined exposure

Imagined exposure was linked to lack of auditory privacy. By this I mean that if conversations could be heard by others on the other side of the curtain, then exposure of the child could be imagined. 12FN gave an example of this:

“If you are going to do a rectal exam then you don’t announce that to everybody in the middle of the ward and go to a quieter area before you actually carry it out, not behind a curtain in the middle of the ward so everyone knows (or imagines) what’s going on.”

Imagined exposure meant that when the screens were drawn back the patient had to deal with the exposure as if they had been actually witnessed (6.10).

Staff felt that children went through different stages of self-consciousness about their bodies. Ways of behaving, or being treated, that were appropriate for a toddler would not be so when the child was older or a teenager. Staff needed to adjust the way they behaved with the children accordingly. Staff described embarrassment as the likely outcome for bodily exposure in older children. Bodily exposure would contravene the normal rules of society (Warren, et al, 2000) that would have been internalized by older children. For those children who were unaware of such taboos, or “too young”, then the nurses acted on their behalf to cover their bodies, “as if” they had an awareness of their dignity (7.7.4).
"They (younger children) have less inhibitions and as people get older, they get more inhibited about their body...Children are quite happy to run around with no pants on, whereas an older child, or an adult won’t do that" (2FN).

Sometimes staff seemed surprised that children allowed them access to their bodies and assumed that the child was happy for them to do so. When I asked student nurse11FSn whether she thought dignity changed as you got older, she replied:

“Some children don’t really care about it do they? They are quite OK about it. I had a twelve-year-old girl, she had abdo. pain and she was incontinent and she was quite OK for me to change her and clean her which was quite surprising ‘cos if I was a twelve year old, I wouldn’t want anyone caring for me.”

11FSn had interpreted the girl’s reaction to her care as being “quite O.K.” by reflecting, as an adult, on her how she might have felt and reacted aged twelve.

Staff were likely to take the lead from parents with regard to norms in bodily exposure. This was a reflection of the findings from the Pilot Study (4.2.8).

6.8.3 Nakedness

9FN acknowledged the fear some children had about being naked, especially when going to the operating theatres (7.7.5.2). She preempted their concerns:

“I automatically, when I ask them to put a gown on to go to theatre say ‘It’s OK you can keep your underwear on’ and for girls, if they are wearing bras and things ‘You’ll have to take your bra off, but it’s OK you can put a gown on’”

The children were reluctant to wear hospital gowns. 9FN commented that the children did not always want to put gowns on:

“You know if they are attached to that T-shirt, then leave it on, or whatever. If they don’t want to take their clothes off, because some of them feel very vulnerable I think, you know, and if that’s the way they want it then that’s fine, and you can usually talk to the staff down in theatre.”
As well as a reaction against the possibility of being naked, I argue that the expectation to comply to dress as directed was resented by children as the control of self presentation (7.7.8).

6.8.4 Bodily awareness

10FN thought that children had “more awareness of their bodies” than adults. She felt “children should not have things done to them” as if others took control over them. On the whole the staff, who were predominantly female, demonstrated a greater awareness of the bodily concerns of the girls (6.5.2).

For example 16FD remarked that children became more aware of their bodies as they get older. She continued to describe conditions that are particularly embarrassing for girls to talk about:

“Talking about different subjects like going to the loo can be very embarrassing, for girls talking about periods, talking about relationships with boys is more embarrassing as they get older.”

5FD also focused on conditions that affected girls and could be more embarrassing than others, such as heavy menstrual bleeding. Prendergast (1992) offers useful insights in the way menstruation is constructed as both individual and social in her discussion of her research in schools. She describes menstruation as needing to be kept in its proper place “in essence totally invisible in a school setting” (p. 85) and the girls’ strategies for keeping it so. Secrets of the body and body privacy were threatened constantly by exposure, observation and examination. In addition, on the ward girls had to ask for pads or tampons thereby bringing attention to something private.

Staff did not mention embarrassment felt by the boys (7.6.6), although 8FN spoke as a parent when she recounted the humiliation of her son when he attended Accident and Emergency with a painful groin. She admitted that “As a nurse I would think it was just an ordinary thing,” rather than being attuned to the potential gender related anxieties.

6.8.5 Legitimization of illness
The staff played a crucial role in verifying whether a child was ill or not. I have called this the "legitimization of illness" (7.8.4). On the ward this legitimization of illness occurred after a series of tests and measurements were performed and samples taken from the body. The child was looked at from the outside and the inside, with the use of X-rays. The parent (usually the mother) was quizzed and the mother attempted to give the right answers. If an anomaly was suspected then the child was admitted, it was acknowledged that the child was ill and became 'legitimately ill' as deemed by the doctor.

It is relevant to note at this point the difference in emphasis, on admission to the children's hospice (4.3.1). In their admission booklet "All about me" (Chase, 2004), parents, and child where possible, are asked for "Indicators of becoming unwell" and "action required." The normal "temperature range" for the child is requested from the parent. The different terminology puts the expert knowledge back into the hands of the parent with the power to interpret signs and symptoms of illness.

Following the legitimization of illness on the ward, the child was relinquished by the parent and the child was "legitimately ill" and came under the care of the medical team. This relinquishing involved both a physical and emotional separation. The child was moved on to the ward away from the parent as the parent gave up their role as main carer. A cannula was positioned soon after admission, almost as a symbol of staff taking charge of the child, and in doing so the bodily boundary (6.8.1) was pierced.

6.8.6 Pain

During my analysis of the data I struggled with where to link the construct of pain. It was not until towards the end of my analysis that I realized that, of course, it should reside in the section on "The Body." This, I suggest, reflects the way pain could be objectified as separate from the subjective reality of the experiencing child. Pain was asked about, and described, but managed in such a way as it was taken away from the control of the child. Staff described past practices and talked about pain in children and how approaches to managing pain had changed over the years:
"For many years there was a tendency for people to say that babies do not feel pain" 14MD.

Staff defined pain and predicted pain. 14MD went on to explain what influenced his decision to use pain relief for procedures on children in his current practice:

"For any painful procedure we use L.A. (local anaesthetic). For children having blood tests we use L.A. unless they are very uncooperative, or may not want to wait that long, so perhaps you've got to go ahead and do the blood test. If I am putting in a chest drain, I always put L.A. in, anything that involves more than just a prick of the skin. If I am putting a drip in or an arterial line in there's no point, 'cos it's just as painful to put in local anaesthetic."

15FD spoke about her approach:

"I think in the olden days, in times gone by, there was this view that babies do not feel pain and there may be a few people around that still believe that, but I think in the Paediatric world ... and people realize that things are painful and in the over ones at least there are things that we usually give...I'm not sure whether Emla® cream is helping the distress in that situation."

The administration of Emla® (2.5% lignocaine and 2.5% prilocaine) cream necessitated applying the cream and "covering it with an occlusive dressing for at least one hour" prior to a procedure such a venepuncture (Northern Neonatal Network Staff: Neonatal Formulary 3, 2001, p. 46). 6

Although staff said that local anaesthetic was given, they cited times when it was not used, suggesting that the potential distress caused by using local anaesthetic precluded its use, even topical cream. Babies were not given local, including topical analgesia as often as older children, nor given sucrose. It seemed that the bodies of babies were conceived of differently from the older children, as if their subjective experience of pain was not the same. Assumptions were made and not questioned about the use of pain relief for babies amongst some of the nursing staff:

6 The Neonatal Formulary was "designed to answer the growing need for compact and up-to-date referenced advice on prescribing drugs, and their safe and accurate nursing administration, in the neonatal period" This was in response to many manufacturers delaying to seek authorization to recommend neonatal use and "advice on use in young children is often non-existent" (Neonatal Network Staff, 2001, p.v).
"Most of the medicines we can give for older children, like numbing cream, we can't use for babies, so a lot of the procedures can be, may be a little more painful for them, um and for things like cannulation and lumbar punctures, it sort of they have to have it done, however painful it is" (7FN).

Use of Emla® is unlicensed for use in infants between one and twelve months and is not recommended in those under one month (British National Formulary, 2005). Nevertheless, Halimaa (2003) reviews the use of Emla® in a cross section of twenty eight studies on infants. She describes a range of pain relieving strategies for premature babies. These included: an environment that is favourable, safe preparation, pain alleviation during the procedure and restoring the babies sense of security after the procedure.

It was recognized that the children did experience pain as a direct result of medical interventions. 2FN said:

"We are renowned for causing a lot of pain. A large amount of pain that children experience is procedural pain."

She continued:

"We must minimize that as much as possible and give good explanations for why we are doing it if some procedure is a painful procedure, do what we can to minimize the pain."

Thus the staff managed the bodies of the children. First the staff defined a child as "ill" through a series of bodily measures and admitted the child after legitimizing illness. Staff controlled the boundaries of the children's bodies and breached their bodily integrity. Staff, particularly the nurses, assumed responsibility for exposure and covering up. Staff also assumed governance of pain by predicting, defining, sometimes causing and alleviating pain.

6.9 Control.

Admission to hospital can be a disempowering experience for many people and experienced as a threat to personal control and choice at a time when they are sick. This imbalance of power was recognized by staff, for example 6FN who said:
"Sometimes its sort of a bit intimidating when we are all doing certain things."

The context of the hospital ward was controlling and the staff played a part in the control of the children. Children could be intimidated by the environment of the hospital ward and 2FN thought that this could stop them from speaking up against something they did not like. Children were able to take limited control in what and how things happened to them. 8FN gave an example of how children could manage large ward rounds:

"Or they will scamper on to Mum's lap and stay buried here until everybody walks out and then one of the doctor's will come back later and just see them on their own. That is their way of maintaining things as they are and 'thank you very much you can all go away.'"

Away from the hospital 10FN tried to give control to the child for out patient treatments and appointments (6.3.3.1):

"The timings for things is important, giving power and control back. An example would be I try and offer children appointments that suit them"

It was interesting that quite a few of the children wanted to be seen at school, with their friends involved as well. 10FN gave the example of a teenage boy who wanted his friends at school to see his line being accessed.

Most of the staff did not talk about power directly, an exception was 10FN who did talk about the power of hospital staff over the children. She described her firm belief that "children should not have things done to them". Instead she advocated a partnership, rather than one side holding knowledge:

"I think knowledge is power. I say to kids, the more you know, the more powerful you become."

Professional power comes from holding knowledge and not sharing. I noted a sense of the separateness of children and their families and the staff. It was interesting to note the physical way this manifested itself in the positioning of staff to patients. This was picked up by one of the consultants who commented that the staff tended to separate
themselves off from the patients by congregating at the nurses’ station, alongside the notes trolley and X-ray screens:

"People do tend to sit behind the desk hiding behind a wall and the children are on the other side of it in the High Dependency Unit" (13MD).

The layout of the ward (figure 9) defined the ownership of discrete areas. The space behind the wall was the "nurses' station". The Parents’ room was a tiny room with a drinks machine, the child’s bed space was occupied by the child and the family, the Play room was for playing. There was no shared space and no free chairs to encourage informal mixing. Interactions between the staff and the children and their families occurred when there was a procedure to be done or information to impart.

6.9.1 “Getting them to do what you want them to do”

As demonstrated in the literature review, there is now a growing literature about the empowerment of the child and involving them in their care. Alderson (1994, p. 52) argues that there is a “gradual trend nowadays towards professionals sharing information with patients, but not yet willing to share decisions with them”

Staff respondents spoke of their own perceived dilemma in a hospital situation, for example 14MD said:

"Children obviously need to have a say in what happens to them, but you have to be careful because if you ask a child whether they want to have a blood test their automatic reaction is 'No, I don't want a blood test!'"

He described the problem of getting the child to do what you want them to do, to which there are the options of coercion and negotiation.

6.9.1.1 Coercion

There were times when procedures were done without the consent of the child. Staff respondents spoke of times when it was necessary to “get on and do it” (11FStN) when they were talking about performing a procedure on a child. 2FN rationalized this by saying:
“You are doing it because you know it’s got to be done.”

Limited time and staff contributed to this approach and meant that procedures could not always be done in an ideal way and physical force was used:

“On the ward at the moment a child needs a cannula so it’s like ‘Come on let’s do it now’ and you don’t give them the time to explain as much as you could if you had plenty of time” (12FN).

Staff respondents described times when the child objected to the procedure, 2FN said:

“You are restraining people, you are holding them down a lot of the time, particularly babies and they are crying”

2FN acknowledged, but felt uneasy with, the power imbalance. A more detailed account of using force came from 11FStN.

“You just got to hold them down and get it done. Trying to put a catheter down his nose to suction something up and there was no way in the world he was having it done and we stood there for two hours. It was on a night shift trying to get it down, so eventually they said ‘Look we can’t force it down him.’ It was awful ‘cos he was screaming and shouting at us. He was nine and mum was in tears because she wanted him to get it done."

She continued:

“Not nice when you hear them moaning like that and cursing at you. Swearing at us and trying to bite us”

Staff respondents described the tension between getting it done and not assaulting the child. As I mentioned in the Literature Review, children remain the only group in the UK not to have legal protection from physical assault (2.3.1). Two of the nurses, both now in specialist roles away from the ward setting, described some of the procedures undertaken on children, as assault. 8FN gave the example of more junior staff needing, and taking, more than one attempt to perform a procedure:

“But often they will have two or three goes because there isn’t another person around to do it. I think then that person’s dignity is taken completely
away because attacking their person and not actually getting anywhere" (8FN).

As a way of clarifying the notion of dignity and its meaning for babies, 10FN returned to the subject of assault and said:

"Dignity for babies is not being assaulted, and we do assault them a lot in the name of medicine, they get the most appalling things done to them..."

In this comment, 10FN confirms her view that the meaning of dignity in children, in this case babies, is the freedom from assault. Force was not, necessarily, objected to by parents. 9FN described instances when the parents are more inclined to use force than the staff:

"You know some parents will say 'Oh just hold them down and give it' and you say 'Well actually, you know, that’s not acceptable. You know, I think we’ve just got talk this through first and see where we get to.'"

Denying the opportunity for their child to respond or object to treatments in this way suggests that the parents could conceive their children as unable to contribute to decisions about their care.

6.9.1.2 “Being held down”

I became aware of a commonly articulated interpretation for a child’s distress at procedures. It was an explanation proffered by the Play Specialist through to the experienced nursing and medical staff. Staff spoke of the dislike babies had for being "held down." For example, 9FN spoke about how she did not like having to hold babies for a lumbar puncture:

"It looks as if you are hurting them. You are not actually hurting them, they just don’t like being held."

15FD also stated:

"I think in the Paediatric world people realize that things are painful and in the over ones at least there are things that we usually give, but I have to say
in my experience, I think that, yes I completely agree that having a blood test hurts, but actually I think that babies dislike being held down."

The medical staff in particular commented on how, in the past, pain experienced by babies went unacknowledged (6.8.6). There still seemed to be some discrepancy between the understanding of pain in children and the provision of pain relief. The belief that babies do not like to be held down may be true, but it may also be a construction. The innocuous sounding “holding down” could be a defence for the staff allowing them to believe that what they were doing was without controversy. The idea that the staff might be deliberately causing pain to the babies and young children might be too uncomfortable to tolerate. It was interesting that since having children of her own, 12FN was less able to tolerate painful procedures on the children. Rather than empathizing directly with the child, she described the greater empathy she felt with parents of sick children:

"When I am holding a child for a procedure, or holding them down to have bloods or a cannula put in, I try to think what that would have been like if that was my little boy" (12FN), and:

"When you hear a child saying to their parent ‘No, Mummy, no’ it pulls a certain part of you that didn’t do that to me before" (12FN).

It was as if she was less able to distance herself from their subjective experiences, including that of pain. 12FN reflected on how her practice had changed with regard to procedures on children since having her own child: “Probably now I would stop doing something much quicker than maybe I would have done in the past.”

6.9.1.3 Negotiation

I was interested to hear about alternative ways of approaching children for procedures. Rather than resorting to force, 15FD spoke about getting children to do what she would like them to by meeting their needs first:

"If you don’t respect the children’s needs then you won’t get the best out of them so in order to get the best out of them you need to make sure they are happy, that they are comfortable, they’ve got toys. They’re occupied, they are not hungry, there are all sorts of things, they’ve got their Mum near them,
so it's making sure you put their interests first and do what you need to do in the context of their needs."

She goes on to acknowledge that this concern for the needs of the child could be beneficial for all parties:

"In some ways it's the self interest because it is what makes them respond best and how they can make it better."

4FP also talked about how to get children to do what you want, she uses the terms 'incentives or bribes'. She recommended:

"Playing games to maybe get the results that you want rather than being straight forward."

12FN advocated using the parent's knowledge of their child to determine their best interests:

"I think it is worth listening to that parent and stating 'What do you think will be best for your child?' and then make an assessment on what you also think."

6.9.2 "Best interests"

The term best interests featured frequently in interviews with the staff and referred to an adult defined reasoning behind a particular choice of treatment option. Best interests seemed to relate to "who knows best" and was linked with the idea of the child as a person in of the future rather than of the moment (6.5.7).

When 15FN stated:

"We do things without their consent, there's no doubt about that!"

This was justified by doing things in the child's best interests:

"I mean sometimes it might be completely inappropriate to completely explain exactly what we are doing to the child but, we would always explain something, but there would, might be, times when it's in the child's best
interest to explain to Mum, have familiar people around and get on and do what you have to do, if it’s not a very nice thing."

7FN talked about babies having procedures:

"They have to have it done, however painful it is. If they are having it done it is for a reason, although its not very nice for them and especially not very nice for their parents who have to be in there."

She appeared not to question the decision for a procedure and empathised more fully with the distress of the parents. Similarly, 6FN rationalized her role as the “Bad Guy” doing procedures on a child. She said:

"It’s hard sometimes, but you always know that it’s in their best interests at the end of the day."

However 12FN saw her rather differently, she spoke about nurses exploring how the child might best be able to participate in their care:

"How they involve the child or the parent in the care. Whether they are listening to the child. Listening to the parent. Challenging the doctors or other professionals that want to do things to the child."

In her role as Matron, 12FN was not always on the ward engaged in the day to day care of the children and their families and was able to stand back and incorporate ideas of best practice into her explanations of negotiating best interests.

In contrast to this perspective, 10FN argued:

"Sometimes we override people’s wishes in what we think are their best interests, but it can’t be in their best interests if they are not prepared to participate in it themselves... that’s stealing your dignity!"

10FN continued on to talk about inserting a naso-gastric tube against the will of a fourteen year old boy:

"If somebody shoved a tube down my nose and I said I don’t want it, I don’t want it, I don’t want it – ‘well you’ve got to have it anyway’. That’s a terrible insult and that devalues you so badly in your own eyes because you have been told whatever you say is worthless."
In this case 10FN explained, the degradation experienced by the boy and his humiliation at having a visible naso-gastric tube, led to a deterioration in his condition. He would not go out of the house and would not let his mother administer feeds via the tube overnight. 10FN removed the tube on the promise of the boy that he would work hard to consume sufficient nutrition.

Alderson (1994, p. 60) in her discussion of children's rights to integrity, is critical of the notion of best interests. She recognizes that best interests, as defined by adults, can complement a child's view of their own right or need, but they may also conflict and states:

"If young children experience unexplained treatment as assault, it opens a credibility gap between the young person's perception of harm, and the adult's intention to benefit" (Alderson, p.60).

Such a breakdown in trust, exacerbated in the strange environment, precipitates feelings of helplessness and being out of control of both events and one's own body.

6.9.3 The power of communication

The dilemma of treating children was made more complicated when the child was very young and had limited ways of communicating their thoughts and feelings. Where the child had a disability, communication could also be an issue. Staff were reluctant to try and communicate directly as explained by 14MD:

"Children with special disability problems et cetera tend to be pushed to one side, because you don’t engage them in the conversation."

Communication by babies could be negated by staff. However, the ability of babies to communicate their needs was recognized by 8FN who said:

"The babies all scream and shout if they don't want their cannulas putting in."

10FN commented on some of the challenges faced by staff in communicating well and gave two reasons for this:
"We aren’t good at listening to what people are telling us and sometimes we think we know best."

4FP described how she might overcome problems when verbal communication was difficult:

"Literally do a practical demonstration of what I am going to do: getting out of bed, using crutches or using stairs. I will often show them, so they know I am not just hauling or mauling them around."

Staff recalled instances when parents could create problems for their child by lack of communication. Difficulties were created for the nurses too when they tried to withhold information from their child, as 2FN explained:

"The parents come in and say ‘I haven’t told them why they are coming into hospital’ and that is really hard and they need to prepare their child."

She goes on to say:

"If they are going to have a blood test, ‘Oh no, you’re not going to have a needle’ and you are holding a child’s hand and the doctor’s ready and the mum’s going ‘No, we’re not going to put a needle in your hand.’"

Communication at the time of the ward round was thought to be difficult for both the child and parents, with parents concentrating and retaining only part of what was said:

"It’s very interesting on the ward round and listening to what is said to parents, and you can see which bit of the information the parents heard. They haven’t listened to half of it. They’ve unfortunately hung on to one drastic little bit that popped out when somebody was just trying to give them statistics or something" (8FN).

8FN also talked about how, in her view, children were not able to fully participate and communicate about their care:

"They are very good at not speaking at all if they...they just shut down completely and they don’t even...The ward round is there and they carry on with their colouring watching TV and completely blocking. I think perhaps
that is their defence, maintaining who they are so they haven’t got to see a whole sea of people, who listen to their chest or prod their tummy."

In an attempt to deal with the intrusion they appeared to opt out. It was as if denying what was happening, could enable them to maintain control. However, this could also have the perverse effect of reinforcing constructions of children as unable to participate in their own care and treatment.

6.10 Witness

The notion of witness implies an “other” who sees and in some way judges what is seen, in keeping with social norms. The gaze of the witness is powerful in inducing feelings of shame and humiliation in those on whom their gaze falls. Approval or disapproval can be directly forthcoming from others or, in older children and adults, these reactions can be internalized (Smith and Cowie, 1991). The importance of the witness, when it comes to the maintenance of dignity, has been noted by other authors, notably Mairis (1994). The importance of the witness and the nature of the witness to dignity evolved from my own pilot work. Here I noted how the public and private lives of the children and their families were continually on show and brought under the scrutiny of not only the staff but also the other families on the ward. Such exposure, and the impact of witnesses, I argued, threatened dignity (Reed, et al, 2003). From my observations of and discussions with the staff in the Main Study, it was apparent that witnessing and witnesses were relevant to their understanding of dignity in hospital.

6.10.1 Legitimate witness.

It was evident that some individuals such as the nurses and doctors, particularly the more senior doctors, and the parents of the child (mainly mothers), seemed to have a greater right to invade the privacy of the child than others, because of their role. These individuals were present and were witnesses at times when the child’s body was exposed and when information concerning the child was shared. Often these witnesses asked permission of the child before being party to any exposure, but not always.

Staff took for granted their access to the children and their bodies as if they were legitimate witnesses. They witnessed the child and family with a medical gaze, judging
the child through a clinical framework with disease situated in specific organs rather than seeing and judging the child and family as social beings (Foucault, 1973). In this way, by adopting the clinical gaze, they were able to ameliorate the otherwise normal reactions of embarrassment and shame for themselves and their patients. Lawler (1991) describes the use of “contextors”, such as a matter of fact approach, by nurses to minimize embarrassment and reconstruct potentially socially embarrassing events as nursing practice.

Staff seemed to understand the difference of gaze and discriminated between legitimate onlookers and others. The others were non-legitimate witnesses without the rights to see or hear matters that were constructed as private. The staff were protective of the children against other onlookers such as the parents of other children and “people” passing through the ward and sought to cover them up. This was described by 12FN:

"Covering them up, not doing things in a busy environment, making sure they are not exposed to other people to look at them, ‘cos even if they (babies) are exposed, people do not have the right to peer in and see what’s going on."

Staff thought that their behaviours helped to maintain the dignity of the patient and family. 4FP described how she thought the dignity of child patients could be maintained by avoiding the gaze of others:

"...preserving their dignity and keeping them isolated from people watching them".

This way of promoting a child’s dignity was expressed in similar terms by 13MD who said:

"Cared for in a way...that they aren’t embarrassed or exposed in any way, either visually or verbally to anyone else."

Some staff were aware that the sheer numbers of people viewing a child could be detrimental. The number of witnesses was key, 16FD explained: "having less people seeing them as possible." One strategy to limit the number of onlookers was described by 6FN. She described how she stepped outside of the curtain during the ward round if she thought it necessary:
“Yeah, sometimes I step outside if there are too many people in there. I try to sort of listen, but it's hard to. Or I will get the information afterwards if I can't hear.”

In her attempt to limit the impact of another person looking on, 6FN would take herself away, even though it left her trying to listen in order to understand what was going on with the patient.

The interest of others was construed, rather than as simple curiosity, to have a negative impact, and be of no benefit to the child and his or her family. This resonated with my unease at seeing sights or hearing information that I thought I should not in my role as researcher, that I had termed this “nosiness” (5.3.3). It was apparent that people, other than staff, did not have a right to exposures, perhaps it was assumed their witnessing might in some way be a threat to the child. I suggest that it could also be a threat to their professional status. The staff respondents often referred to onlookers who were neither non medical/nursing staff nor immediate family members as “people” whose only motive seemed to be nosiness.

Staff did not always use their privileged access to witnessing with the utmost sensitivity and, in so doing, put at risk the dignity of the child and family. One such example comes from observation notes of 4.10.05:

*Three junior doctors are crowding round in the corridor outside Ambulatory Care. “We're listening to croup,” one explains to the registrar. “When he stops crying! We're listening to croup, he's not very happy!***

Rather than applying a clinical gaze, I argue that they used their legitimated access to the child for their own benefit and learning, in this case in identifying a child with croup. Although unintentional, by bringing the child to the attention of others, confidentiality was undermined and they objectified the child by not connecting to his suffering or that of the parent.

6.10.2 Exposure.
Television portrays hospital life through drama and viewers are able to witness events as if they were real life. Sometimes there were particular incidents of high drama on the ward that drew the attention of others as described by 12FN:

"It's always very exciting when there is a priority on the ward, or on SCBU (Special Care Baby Unit), that people automatically want to know what is going on and at the end of the day there's somebody's baby, or child, at the bottom of that resus."

I wondered whether it would be reasonable for staff to admit to feelings of excitement at times of emergency. I speculated that it would not be 'appropriate' for others on the ward to experience excitement at witnessing a resuscitation.

The presence of others on the ward made for perceived or imagined witnesses from the perspective of the staff. Here the "perceived witness" refers to an other in the vicinity of whom the member of staff, was aware and who could potentially be watching, listening and forming opinions of what they witnessed. The imagined witness refers more the scrutiny of one's own value system (Shotton and Seedhouse, 1998), or in psychoanalytic terms, an internalized other. This notion of perceived and imagined witnesses provided the basis of pulling the curtains, taking families to a different room for a discussion and other manoeuvres to protect privacy from what other people might see or hear. The staff also talked about their sense of themselves being watched and judged by those on the ward. 6FN hinted at her own unease at being watched by several people when she was undertaking a clinical procedure that was new to her. It was as if her personal and professional status could be threatened, or even her dignity:

"So they were all looking at what you're doing...and I actually felt comfortable as they were all so lovely".

It was her perception of the nature or motive of the onlooking witnesses, in this instance, that let 6FN feel comfortable in what she was doing, rather than just her ability to do the procedure.

I was aware of my own role as a witness (5.3.3) and my own legitimacy as a witness. I was aware of my own sense of unease and being on show as a researcher. In talking with the staff I was made increasingly aware of my impact as a witness on them. I
wondered if the restrictions imposed on me, such as no access to records and access to children limited by the nurse in charge, was in response to my power as a witness and an attempt to control what I could witness.

6.10.3 Privacy.

As I have mentioned (6.6.1) the nurses in particular seem to equate privacy with dignity. The two words were often used together and interchangeably by the nurses in interview. Privacy seemed to be a more concrete, doable concept, or at least understood as such by the nurses and meant absence of non-legitimate witnesses. Nevertheless the provision of privacy in hospital posed a dilemma, as highlighted by two of the staff respondents, and evident through observation. The requirement for constant surveillance compromised privacy. For example 7FN said:

"I don’t think its always the case that they are getting the privacy that they would want because, especially in the High Dependency Bay, the curtains cannot be, I don’t think they should be closed overnight, 'cos you need to 'keep an eye on them'. But I don’t think there is enough privacy, but I don’t know how it could be helped really, because you have to observe the children otherwise there is no real point in them being there to an extent, you need to keep an eye of them overnight."

If their condition was judged to necessitate constant observation, curtains were not used to obscure a child. 4FP was referring to the Special Care Baby Unit when she said:

"It is not a safe environment to be putting curtains round and having the children not being 'eye-balled.'"

13MD was talking about promoting dignity for children when he stated:

"I think we do have to compromise in areas because you have to accept that children have to be observed and one way that I am keen to do that is to try and observe the children as inobtrusively as possible."

Likewise in the side rooms, blinds were placed at the windows to give privacy to the patients and their families, but as 7FN said:
"We have signs on all of the cubicles, or a lot of the cubicles to say can you leave the curtain up, so that we can keep an eye on them."

The need for surveillance was superior to the need for privacy.

6.10.3.1 Young children and witnesses

Staff thought that young children were unaware of privacy, or lack of it and that the older children were more aware of privacy and witnesses. 5FN stated:

"The older you get the more aware you are that people are listening in, you are more aware that they can hear what 's being said about me or they can see what they are doing"

Although staff unanimously thought that children developed a sense of privacy and of self-consciousness, they differed in what age they thought this became important. This was consistent with the attitudes of the staff in the Pilot Study (4.2.10). When asked what she thought was really important for children in hospital, 5FN answered:

"Knowing that people aren't going to be looking at them, 'cos even little three year olds can be quite self conscious."

Staff agreed that privacy and protection from exposure to others (witnesses) was as important as in older children or adults. It was as if as well as children having the right to be protected from the gaze of others, they also needed protection from becoming witnesses and being exposed to sights inappropriately. Staff reported that this right was not always adhered to as much for babies and young children as it might be:

"(Babies) have the same rights as any child, people forget ‘they are only babies, so it doesn't matter’, it’s trying to keep them covered. The baby is probably not too aware of what’s going on but Mum and Dad are and, I think more so in special care, they are just seen as a baby and not as an individual and exposed more than they need to be" (12FN).

4FP felt that it was part of her role to protect the child due to their limited awareness.

6.10.4 Confidentiality
Diagnoses were kept confidential from me as researcher and I was not allowed access to medical notes. 7FN described the importance of confidentiality during our discussions about dignity:

"Be careful what you say in front of other people, information sharing, that sort of thing, just being careful who you speak to..."

I mention in my discussion of the researcher role how I would listen out to remarks made by respondents that were in effect inadvertent references to me. It was at that point in this discussion with 7FN, that I wondered if she was referring to her reservations in talking to me.

5FN commented on the environment and the difficulties in maintaining confidentiality, as if information could easily become available to the wrong people:

"So you've got parents not necessarily purposefully listening in but they think, 'Oh I wonder what that means?' They pick things up, you hope they wouldn't but it's a small room and a lot of people."

Some of the staff respondents reflected upon privacy and witnesses in the context of the ward round:

"...a lot of issues to do with privacy are to do with the ward round. A whole entourage of people come round, tuck themselves behind the curtains: everybody can hear what's being said a foot away from them on the other side of the curtains" (2FN).

She continued:

"Sometimes you've got a consultant, sometimes two Regs (Registrar) and two SHOs (Senior House Officers) without the medical students and the nurse in that area and sometimes the nurse in charge" (2FN).

During my observations, I found that the carers (n=3), present in loco parentis, seemed more forthcoming with medical information about their charges than I would have expected from my discussions with parents. The corresponding easy way information was passed to carers was picked up by one of the sisters on the ward who stated:
"Rightly or wrongly, we become very trusting of those people and give them information and sometimes you think "Oh but they are not the parent and I told them what the doctor said on the ward round" (2FN).

This indicator, suggesting a freer offering and exchange of information by carers about children in their care, may warrant further investigation.

6.10.5 Habituation

Some children were required to undergo many examinations by professionals. This began to become normal and no longer strange, they became less wary as they became habituated to examinations. They become desensitized to the presence of witnesses at the exposure of their bodies. 10FN commented on how some children seemed more relaxed about showing their bodies:

"...more often in children with chronic need who are hospitalized and used to this awful indignity of being examined constantly and constantly being surrounded by people and not being allowed the privilege of having it done one to one."

5FN thought that babies too were sometimes used as exhibits:

"You quite often see babies stripped down, they don't pull the curtains round to look at them unless... if it's just weighing them or looking at her belly... carted around, half naked to get weighed... I wouldn't personally like my baby shown to everyone and be examined in front of twenty people."

I wondered if she had challenged this way of handling babies. Some children became habituated to being exposed and examined by numerous doctors, nurses and medical students. For medical student examinations they were given money and expenses (14MD). I have chosen a term that is associated with the sexual abuse of children, that of grooming. It was as if children were unwittingly "groomed" to become willing exhibits for medical students. 14MD talked about using "cases" in exams:

7 I have chosen the term “grooming” that is associated with the sexual abuse of children. It is also used as term to mean the preparation of children for a future role (Wikipedia, 2007). I hope the term is not offensive, as no sexual connotation is meant. However, "grooming “ does accentuate the potentially abusive use of children for examinations.
"Some children I would never bring to exams because I know they would be embarrassed or humiliated, particularly teenagers...other children love it."

This apparent enjoyment could be capitalized upon by staff who may want to 'use the child' (my expression) to teach students. In doing this, the child was encouraged in showing their bodies, their symptoms, their medical curiosities and receive attention for being medical spectacles; a situation reminiscent of the experiences of John Merrick (2.2.8). Featherstone, et al (2005, p.572) in their discussion of dysmorphology conclude that such "spectacular display" and "oracular pronouncement" are long-standing features of medical knowledge as is the importance of "a deeply entrenched visual and oral culture in the creation and transmission of medical knowledge."

6.11 Performance of Dignity

Staff respondents, when they asked what they thought dignity meant, frequently explained their understanding by operationalizing dignity. For example, they talked about using curtains to maintain privacy and gowns to cover exposed bodies. In this section I describe how dignity is done, or carried out as described by staff. I have applied a symbolic interactionist eye (Goffman, 1971) to draw out the production of dignity as a social performance, as if the staff were the players or actors. The patients and their families become members of the audience, periodically brought in to play a part. I have drawn upon vocabulary from the stage to draw out the theatricality of the actions and rituals of the staff together with the props for dignity, their symbolic meaning and dignity rules.

6.11.1 Dignity props

I have used the term dignity "props" to apply to items, or artifacts, linked with the promotion and maintenance of dignity on the ward. These are items that were used by the actors for the production of dignity. They include: gowns, sheets (4FP), curtains, blankets (5FN) covers (11FStN), blinds at cubicles (2FN). They are mainly concerned with covering the body or concealing a body in a physical way from others. These props were, at least in part, symbolic; they symbolized dignity was being attended to. The notion of hospital furniture and items being used in this way is illustrated by 4FP when
asked what role do staff have in the promotion of dignity? She said, displaying her physiotherapy training:

“Making sure they can help out with providing bits of equipment to provide dignity”.

6.11.1.1 Curtains and symbolism

There were a number of props of dignity, one of the main props being the curtains that enclose a bed space, keeping one bed and its occupant separate from the next. When asked about dignity and patients, curtains were mentioned by all staff respondents as a way of promoting dignity. For example when I asked: “Do you think dignity changes as you grow up?” 9FN explained her role in maintaining that dignity by saying:

“I would put curtains round whether it was a baby, or whether it was an adult, or whether it was a teenager.”

Nurses in particular talked about curtains and their role in maintaining privacy and shutting out the eyes of non legitimate witnesses. In particular, they talked about covering up bodies:

“Keeping them covered if they are going to theatre or whatever, protecting them from undue and unnecessary attention” (5FN).

7FN stressed: “just the importance of using curtains round beds” when talking about dignity and children, and later when discussing promoting dignity:

“Maybe some leaflets or posters about advertising keeping the curtains drawn.”

Curtains, therefore, were integral to the performance of dignity. For some bodily functions, curtains were viewed as essential as 7FN described:

“…there are certain things like toileting, I’ve never known curtains not to be closed. I’ve always seen curtains pulled round if they are using a bedpan or things like that.”
Nevertheless, curtains were not always used to screen patients during examinations, particularly in the Ambulatory Care bay as I recorded in my observation diary 13.04.05:

12.30hrs: In Ambulatory Care a child (cm4003) comes in for an egg challenge to see if he is allergic to eggs. Cm3002 continues to look on, standing very close by – he should be off home now. (The doctor) continues and examines cm4003’s tummy, no screens are pulled. The little boy giggles helplessly as his tummy is felt.

This supports the idea of Ambulatory Care as a transitional (6.2.3) or liminal space where the rules and rituals of the ward were not so embedded.

Despite suggesting curtains as an essential item for the preservation of privacy, the staff recognized that curtains did not maintain privacy, nor confidentiality, as 8FN described:

“In the main wards it gets very easy to be blasé with people about things, and forget that everyone can hear what everyone else is saying. You are asking people to have a suppository, or whatever, it’s just not very... You can forget that the curtains aren’t actually... so when the curtains go back, everyone knows what’s been going on behind the curtains with that person or family.”

Equally when I asked 5FN whether she thought it was always possible to provide dignity for children on the ward. She said:

“As far as the physical sort of things, they’ve got the curtains and everything, so they are out of sight, so that sort of thing the answer is ‘yes’. But it is extremely easy to overhear conversations between doctors and patients and parents even if you are on the other side of the ward, you could still hear quite clearly what is being said.”

Similarly 1MN said:

“...to be able to have someone listening in to their conversation in whatever sense, even with the curtains round, is not ideal.”

2FN concurred:

“The doctors do the ward round, they go in there, whip the curtains round thinking they’ve got privacy, but everyone in that room can hear that conversation.”
And later:

“The person in the next bed can't see you being examined, but they hear them ask “Have you had your bowels open?” or “Have you started your periods yet?” (2FN).

Despite having considerable limitations in terms of keeping actual privacy, the curtains seemed to have a number of symbolic meanings. I argue that it is the symbolic that are the most important in promoting dignity. These symbolic meanings are important because they were shared by the staff and the parents and to a lesser extent the children. There seemed to be three main meanings to curtains:

i). They signify a personal/private event.

ii). They protect the patient behind the curtains and the potential onlooker.

iii). They contain.

These meanings are elaborated below:

i). When the curtains are drawn around a bed space it meant that something of a personal, or private, nature was going to take place, such as when a consultant arrived during a ward round. This could also be used to indicate to extra visitors that they should leave. Drawing curtains could lead to additional attention being attracted to that bed space by other patients and parents. The bed space became identified as a place where exposure, of one sort or another, to those within the curtain, was expected and okay as the norms of social interaction were suspended.

This meaning of curtains was not always fully understood by the child patients. For example, 16FD seemed surprised when she said:

“She was obviously very embarrassed taking her clothes off even though it was behind curtains and it was only me and one of the student nurses there.”

It was as if the doctor did not perceive that perhaps the girl, did not appreciate the change in social context in the same way as the doctor. She still felt on show in front of two women, despite the curtains.
ii). Curtains acted to protect patients, in a largely symbolic way, as they hid the patient from unwanted witnesses. They also protected the witnesses from unwanted sights, although not sounds. In addition the witness was not required to respond to what is going on because they are symbolically shut out.

iii). Curtains symbolically contained an event, whether it be a containment of emotion such as people crying, the exchange of confidential information for example during clerking in, or bodily functions for example, excretion. 13MD spoke of the need for containment when he said:

"... allowing the child to express its emotions or concerns whether screaming or crying in a protective environment rather than showing them up on the ward, which is why we've got two treatment rooms so we can put children in those rooms to do tests and things."

6.11.1.2 Gowns

Gowns were used to cover as much of the body as possible, often before or immediately after theatre, but also if other clothing was inappropriate. The gowns were long sleeved and open down the back with a tie at the top and were worn by boys and girls. The principle, or rule, of covering up could be maintained when gowns were used. However, although the front was covered, any movement could leave the back exposed. 5FN explained how she used gowns to protect a child going to theatre:

"Keeping them covered if they are a child that's going to theatre, protecting them from undue and unnecessary attention."

4FP talked about how the gown was used to protect dignity on another occasion:

"A little boy who was in the other day... he wore a gown, so it wasn't too bad, but he couldn't wear underwear 'cos of the drain that was coming out was actually causing him more discomfort, having his underwear on, than not. So he was getting up or walking around and yes, we were protecting his dignity by making sure the gown wasn't open."

4FP continued to talk about how she would remind children and their parents about how they could play a part in preserving dignity and conform to the social norms of the ward with these props:
“why don’t you draw the curtains round? or do you need a hospital
gown?...Do you want a sheet, I know you are hot...”

6.11.2 Rules of dignity

There were certain agreed rules concerning the promotion of dignity and what needed to
be done to ensure its protection. These are largely rules to do with upholding privacy
and primarily visual privacy. There were some procedures or events that always seemed
to result in curtains being drawn (6.11.12):

“There are certain things like toileting, I've never known curtains not to be
closed, I've always seen curtains pulled around if they are using a bedpan or
things like that” (7FN).

On other occasions it was left to the judgment of the staff and seemed to be a matter of
personal judgment. There were a hierarchy of rules and some rules could be overridden
in certain circumstances. The rule that permitted children and their families to pull the
curtains around them to promote privacy was secondary to the rule that curtains are kept
open at night for observation purposes. Indeed this rule was written down and displayed
in every bay, but this rule seemed contrary to the need for privacy. This rule was
contentious amongst the children and parents who stayed overnight and wanted privacy
while they slept.

6.12 Emotion work.

The emotion work (Hochschild, 1983) of nurses has been the focus of a number of
research studies (Smith, 1992; Staden, 1998; Bolton, 2000). Nursing staff talked in this
study about the emotional work they undertook to perform as nurses. They described the
ways they might do this in their interactions with children and their parents, that I
categorized as:

.1) Tuning in
.2) Moderating
.3) Detachment/rationalising
.4) Integration
6.12.1 Tuning in

“Tuning in” refers to the way nurses described how they might use their selves to understand others. This was seen as important in honouring the dignity of another. 7FN was talking about the need for good communication to promote dignity when she said:

“To find out how the child is, what they are experiencing and how they are feeling and getting on the same wavelength as them.”

When 1MN talked about dignity he described it as “maintaining my own sense of personal will and choice.” This was what he used for his yardstick when he determined what another might need in terms of dignity, he continued:

“And I’ve got that and I anticipate that for other people.”

7FN was able to anticipate the discomfort felt by children who had to have the curtains drawn back at night:

“I know I think if it was me I’d want to be keeping myself, well you know, keeping the curtains closed a bit more.”

Experience of similar patients and circumstances could assist with tuning in. 9FN described how her experience had led her to be able to pre-empt the concerns of a child, without the need for them to have to speak out or feel embarrassed (6.8.3):

“If you are taking children to theatre or something, particularly the sort of ten to fourteen year old children, you know I automatically, when I ask them to put a gown on to go to theatre say ‘It’s OK, you can keep your underwear on’.”

Staff recognized the emotional work that they had to do as part of their role on the children’s ward, but not all staff were thought to be as capable as others in undertaking this sort of work. 8FN thought that some doctors and nurses were more “in tune with other people’s feelings” than others. She thought that some junior doctors found the children:
"...very scary I think, because they are frightened of them they don't come across very well, 'cos of their own feelings of not being able to cope."

8FN speculated that some junior doctors, in particular, did not engage with the children emotionally because of a lack of confidence.

6.12.2 Moderating

Moderating applies to the way the nurses described a personal restraint in their dealings with their child patients. This included “trying to give them their own space” and “giving them time to themselves and with their families” (7FN). 1MN said:

“Again with younger children very very hard in terms of communication, but it’s anticipating, showing respect in terms of, rather than just diving in, explaining what you are doing.”

In this way he described how he would make a choice about the most appropriate way to perform dignity. On occasion, this could be to the sublimation of nurses' own feelings.

As they moderated their behaviours, staff might also compensate for the child in their care whom they felt might be vulnerable in terms of dignity. 4FP spoke about how she understood dignity and how she tried to understand the children and then treat them appropriately:

"...awareness of what the person must be going through that you are treating, in the sense that you are treating them, preserving their dignity and keeping them isolated from people watching them."

Moderating involved a sense of understanding the other, the child, and also allowing them opportunity to express themselves, almost as one might if in conversation.

6.12.3 Detachment

Staff spoke of strategies they had acquired that seemed to protect themselves when they were undertaking a procedure on the child such as detachment. This detachment was often associated with the rationalization of the child's best interest (6.9.2). Staff spoke of ways they rationalized painful procedures on children by describing events as
in the child’s best interest. Detachment was a useful way for the staff to protect themselves, however detachment could be used to remove, emotionally, the member of staff from the experience of the child and parent. Sometimes this could be in a way that was unhelpful. For example, detachment led staff to make assumptions about the child or the parent in a way that was not questioned. During our discussions, 2FN reflected on whether she was sufficiently engaged when she said:

“I go in and I say ‘Do you mind if a student comes in with me to watch?’ But then you think well maybe just because I am asking them, maybe they are just going to say yes anyway.”

From the ethnographer’s point of view there is much data to be found in questioning taken for granted ways. Some of the staff responded in ways that made assumptions about the children and their families and the hospital environment and I wondered whether this was also a way of detaching. This was especially common in the younger, or more recently qualified nurses, who would sometimes respond to my questions with what I came to term ‘textbook assumptions’. This was when the respondents would answer in such a way as if learned from a textbook and had applied this knowledge directly and unquestioningly to their working environment. Both respondents, 1MN and 7FN, talked about the need for “carrying on the child’s normal routines.” When asked “What things are really important for children when they are in hospital?” 1MN replied: “having an environment that is as close to home as possible.” He included routines, access to friends and family and toys. Neither participant questioned whether, in reality, the environment of the hospital ward was anything like the homes from which the children came (6.2.4). It was curious on reflection that I did not challenge these comments. At one level I did not want to confront them with the reality, as I perceived it, that the hospital ward was likely to be very different from the homes of the children. In this sense I experienced the ease of colluding with their textbook assumption.

On another occasion I asked 7FN how children might be able to promote their own dignity. She replied:

“Asking their opinions on what they want is really the best thing, giving them a voice on their opinions really.”

When I asked if the children are able to do this she admitted “some”, but acknowledged:
“Sometimes it can be very difficult knowing exactly what they are thinking or what they want”.

She continued:

“By getting to know the child, hopefully they can sort of, they can start to sort of tell you what they want.”

This seemed to be a textbook assumption, as at other times staff commented on the very fast turnover and the limited opportunity to get to know the children. Indeed this was my experience as a researcher. Sometimes the assumptions and answers put forward by the interviewees were idealistic assumptions when the scene is described in an idealistic way or in a rosy light. An example of this is when 1MN was talking about the parents of children with conditions requiring long hospital stays:

“Parents whose children are severely disabled, they come in and you know the parents need to have a break and they are happy to go home and know that their baby is left here.”

He did not acknowledge any ambivalence or grief on the part of the parent in leaving their child. In so doing he remained detached from the potential emotional upheaval of the parents. I have described similar situations elsewhere (6.8.6) where assumptions seemed to preclude other interpretations of events, for example when I discussed the withholding of topical analgesia for babies prior to procedures.

6.12.4 Integration

Integration applies to when staff were able to use their experiences, such as being a mother, to inform their practice. For example, 12FN spoke about her conflicting feelings in her role of nurse and of mother as she gave intravenous antibiotics to her own child at home. She talked about how, on the ward, she would detach herself from someone else’s child, but her experience of having her own child had changed her:

“You hear what they are saying, but I think as your child it is very different...when you hear a child saying to a parent ‘No, Mummy no’ it pulls a certain part of you that didn’t do that to me before.”
They are able to use their own experiences to acquire insights and understanding of the lives of others. They were able to hold, often conflicting, experiences in performing their role as a health professional without detaching from one or another.

6.13 Being Human

Humanness was something that was talked about by the parents in particular, but also recognized by 14MD when he talked about the application of dignity in a hospital setting. In his response to “What do you understand by the term dignity?” he said:

“In a hospital setting, it is ensuring that the patient does not become an object, that we treat them as a human being.”

Respect for the child as another human being was demonstrable by the way care and treatment was delivered. It concerned recognizing the needs of the individual person, even if they were very young. Their humanness was acknowledged by treating them in a way that was socially appropriate, for example allowing the child bodily privacy. Thereby their extrinsic dignity was attended to.

15FD highlighted the need to limit the power health professionals could wield over children:

“Not stripping their clothes off with everybody surrounding them, asking them before you do things to them...they have the right to have their food and not be interrupted.”

8FD emphasized the need to empathize with the child and family, rather than seeing them as a job to do:

“How much you respect other people’s thoughts and wishes and think about them not just as things on a list.”

14MD recognized that being in hospital makes patients vulnerable to having any rights denied:

“They (patients) are entitled to the same rights as anybody outside hospital”
The potential to forget the humanness of the patient was acknowledged and described by two of the more senior nurses. 2FN talked about her fear that she might become hardened to the reactions of the children in her care through time. When discussing what it was like holding children for procedures she said:

“Not very nice and I worry that the longer I do it the hardened I get to it.”

12FN was concerned that forgetting the individual person was a response to a preoccupation with the task in hand:

“Sometimes you are so preoccupied with wanting to carry out what you need to do, that you forget that underneath the pile of blankets is a child under there.”

Lack of time was thought to limit effective communication, building relationships and as a consequence honoring the humanness of the children:

“I think sometimes we explain things and go racing off an doing it and we don’t stop at any stage and check whether they really understand” (12FN).

Time constraints also stifled the opportunity to talk to people and to get to know them and find out any concerns that they may have. 2FN expressed this when she said:

"Taking time out to actually sit down and talk to people and say “How are you feeling, do you understand what is happening? That’s the sort of thing that gets pushed to the bottom of the list, because as long as they have had their drugs and their obs. (observations), what people see as the essential things done, that talking to people is seen as a nicety that you don’t always have time for."

The perceived limitations of time were thought to undermine nursing care. The nurses, in particular, described a tension between getting the job done and using time to acknowledge patients as people. It was as if they could be more human if they had the time.

6.13.1 Babies are less human
Babies are unable to communicate their needs verbally. They are unable to move themselves around by walking and sitting up, they are small and their daily living needs have to be met through another. This makes them very vulnerable to being overlooked in terms of dignity. I left my question about babies in the interviews intentionally vague to see how the respondents would interpret my meaning about babies and their dignity. The vulnerability of babies was acknowledged by 12FN:

"They are only babies, so people think it doesn't matter."

And later:

"People think 'Oh it's a baby we can just go ahead and do it."

This illustrates, I argue, how babies can be conceptualized as less than full people with dignity (Alderson, 1994). Constructing children as in the process of 'becoming' fully fledged human adults renders children in a position relative and marginal to adults. This is an argument central to is the new sociology of childhood (James, Jenks and Prout, 1998) Alderson's discussion (1994) relating to integrity, demonstrates how such ways of conceptualizing children can allow them to be acted upon invasively. She argues that if children are conceived as having "little sense of self versus other, then invading the child's body or mind hardly matters."

Several of the nurses spoke about the need to prevent bodily exposure including babies. 5FN thought that although the babies might not mind being exposed their parents may feel otherwise:

"People tend to forget, they think they are babies and don't mind, but I suppose they don't think about the parents in front of you."

In saying this 5FN was advocating for a baby to be treated in a way that is socially appropriate and denotes respect for them as person, primarily for the benefit of the parent. Where babies and children were conceived of as being less human, dignity was performed in such a way as to appease the parent. The dignity of the child was relative to that of the adult (6.7.1). Consultant 15FD commented:
Termination of pregnancy, that shows babies no dignity whatsoever does it?"

For some children every attempt is made to help them continue to live. The lives of other children are ended before they are born. The humanity of the child is based upon the age, in weeks of the child, its potential for future productive life and most importantly, I argue, the value the parents attribute to their lives and their ability to communicate this to the staff who have the expertise to preserve it.

6.13.2 Stigma

Stigma is understood by Goffman (1963) as a negative appraisal of those attributes of an individual that signal difference from an assumed norm. The discrediting affect of stigma “spoils” the social identity of the individual. Highly visible stigmatizing symbols can attract unwanted public attention (Craig and Scambler, 2005). Goffman describes courtesy stigma to describe the way stigma extends to include those individuals such as parents who are associated and involved with the affected individual.

There is a stigma attached to those children who do not meet the highly valued “gold standard” of the normal child. The raft of measurements that are performed on children, leaves many falling outside the norm. Testing begins pre-natally. 15FD talked about stigma in these terms:

"Downs syndrome is something that we can sort of test for, then it’s viewed as kind of this stigma in society and people more and more want, you know the perfect family and the perfect child and that’s quite hard for people sometimes."

Other children, rather than being born with a stigmatizing condition others may develop stigmatizing conditions. 10FN talked about epilepsy:

"The terrible stigma attached to epilepsy, that impinges on your dignity terribly" 10FN used the term “Epie” to describe how children can be defined by their condition.

Children with stigmatizing conditions were attributed dignity relative to their condition (6.7.1). The very nature of some conditions render the experiencing children in some
ways less dignified. Epilepsy is a condition associated with loss of bodily control, including incontinence, that is central to an extrinsic understanding of dignity.

6.13.3 Prioritizing dignity

Respondents alluded to the notion of dignity for children being desirable rather than essential. 14MD talked about his priorities when a child is first admitted, about dignity, and his gaze as the child's doctor:

"Maybe not the first thing someone would think about, when a child comes into hospital they come in with a condition, they come in with a condition that needs specific treatment, you give them that treatment and you send them out. It's not necessarily the first thing, taking a history from them, you are not necessarily thinking about their dignity, maybe you should be, but obviously what you are concentrating on, their medical problem."

It was as if in adopting a medical gaze, the children could not be considered and seen as anything other than "a medical problem."

10FN commented on the way dignity could be of lower priority when the health professional was feeling under pressure themselves, with their concern focused upon their own feelings and ability to cope. She explained:

"When you are a 25 year old in a stressful situation as a medic and you think that something has to be done and you are panicking about it and it's a fourteen year old, you don't care about their dignity, you are more worried about your own stress and whether you can get a line in."

10FN seemed critical of the approach of some of the junior doctors. However, there were times when the need for immediate treatment to save the life of a child could compromise their dignity.

It was also suggested that parents do not always see the dignity of their child (even if they could articulate it) as their priority. 14MD suggested:

"(Parents) are too much in awe of the hospital environment, consultants, doctors and nurses, what have you, to actually think about that and often
they are too worried about their poorly child to consider dignity as an essential item."

Thus, with their emotions elsewhere, the parent advocate (6.4.1.1) could be put in a position where they were unable to speak up for the dignity of their child (7.5.2.2).

Despite being denied access to ethnographic research at the hospice, there was evidence from reviewing the associated literature from the hospice of an alternative construction of the child. The "Philosophy" of the organization included the respect for the rights and individuality of all children, "including the spiritual beliefs of an individual, religious or otherwise that gives their life meaning." When future orientation is not appropriate and death is inevitable and anticipated, then the humanness of the child is lauded and dignity becomes essential. Preserving dignity at the time of death is an attempt to acknowledge the person they were before it is too late, and to acknowledge the value that child had to their family, particularly parents and friends.

6.14 Summary of Chapter Six: The Voices of the Staff

This chapter reflects the voices and behaviours of the staff on the children’s ward. The first section describes the context and the second section how the meaning of dignity is understood and constructed on the children’s ward.

The ward environment provided the backdrop and the context for experiences on the ward. The importance of the environment for the child and their family was acknowledged by the staff. Staff were conscious of public and private areas and made use of them according to how they interpreted the needs of the patient, resources and time. Private areas could contain events and offer a refuge from witnesses. The Ambulatory Care bay was the most public area. It was also a liminal area, a place of transition for the children, from well to sick. Ambulatory Care was also an area where the rules of dignity were not always adhered to.

Staff acknowledged that the environment was "alien" and strange to children and their families. They recognized that the children had to cope with many strangers during their stay. Staff attempted to normalize the ward with items that they thought children would find familiar. Staff advocated keeping to routines as one way of dealing with admission.
It was clear that there have been considerable changes to the role of the children's nurse in recent years and this was reflected in the discussions with the nurses. They welcomed some of these changes, such as increased parental presence, as they thought it benefited the children. Having the parents present assisted them with the day to day care of the children at a time when the role of qualified nurses has become more procedure based and the student nurse supernumerary. However, they regretted the change in the relationships they were able to build with the children directly as they found such relationships rewarding.

Another factor that had influenced the relationships the nurses had with the children was the fast throughput of patients and reduced length of stay. These short stays were characterized by intense activity in order to get the child to theatre at the required time and the associated paperwork. Lack of time and busyness were factors reported particularly by the more senior staff as something that affected the care they would like to offer the children.

Parents have taken the place of the nurses in the day to day caring for the child. This has led to an indirect communication between the health professionals and the child. Control over the child has been shifted from the health professionals to a point where negotiation with the parent over treatment and care has become the norm.

Family centred care has become integral to a sanctioning of a greater involvement of parents in the care of their children in hospital. This has resulted in a triangular relationship between staff, parents and the child. Staff thought that this change in emphasis was of benefit to children and staff looking after them. They cited a clearer understanding of the child's needs through communicating with parents, guidance of how to approach the child and negotiation. There was a risk that the ease of communication with the parent could divert attention away from the child themselves.

The staff recognized that it was a difficult role to be the resident parent of a sick child, especially for parents new to the hospital environment. Staff saw the parents as advocates for their child, but some felt the role was not made clear enough to parents.
Some staff described unease at undertaking painful procedures on the children or holding them for such a procedure. The decisions regarding the presence of parents at painful procedures were led by the health professional undertaking the procedure. Staff were sensitive about being watched by the parents. Nurses noted the impact of having their own children on their feelings and actions when looking after the children.

Children were conceptualized broadly as short stay admissions, such as those needing tonsillectomies, or having more complex medical needs, needing repeated or longer stays, such as those with oncological conditions.

Staff felt able to build and enjoy better relationships with the children and families who were there more often. Staff thought there was reciprocity of these feelings, for example they thought that parents and children would be pleased to see them.

The children were mixed by gender. Staff expressed a greater awareness of the issues girls might have in relation to being in hospital. None of the staff commented on female nurses and doctors caring for young male patients. This may also be due to the way the threat of men to young girls is constructed at a societal level, rather than women and men being a threat to young men. It may also be an indication of a female centric awareness of issues of gender and sexuality on the ward.

Staff used age to determine a variety of care and treatment options based upon a norm for that age. This was less appropriate for children with special learning needs and the nurses confirmed that they relied upon their parents to help them understand their child. Despite referring to ‘the parents’, it was mainly the mothers who were present for the majority of the time and it was through the mothers that the staff conceptualized and gained access to the child. The constructs of something to be observed and someone’s possession surfaced during the interviews. Together with the construct of the care of children to be future oriented, these constructs contributed to the child being cared for in a way that could negate the present real experience for the child. This was in contrast to the way children acknowledged to be “life-limited” were conceptualized in the hospice. It should be remembered that “life-limited” children will still attend a District General Hospital for acute illness.
Staff respondents found answering what dignity meant difficult. They gave a range of responses based upon the principle of dignity as a basic human right. They thought that a denial of dignity could include torture and the humiliation of exposure, how one could protect the dignity of another through privacy and confidentiality and how dignity could be promoted through giving choice and respect for the individual. They acknowledged the interactional nature of dignity, for example they spoke of using themselves to understand another.

Their responses tended to reflect their role on the ward with doctors explaining dignity through principle, the junior nurses, at the ‘coal face’, through the protection and doing of dignity and the more experienced nurses through the interactional nature of dignity. The specialist nurses, who worked away from the ward in more autonomous roles, spoke about the promotion of autonomy and dignity.

Respondents revealed theories about how dignity evolves, changes and is learned. It seemed that dignity was thought to be both relative and context dependent. The staff described a dualism of dignity as something that evolves, as well as something that is inherent in every human being. This seemed like an important dualism, reflected in the literature, that led me to think about dignity in terms of extrinsic dignity and intrinsic dignity.

The body of the child in hospital was observed and accessed as required in order to make them well. The boundaries of the children’s bodies were often physically breached with cannulae, naso gastric tubes, catheters and drainage tubes. I have interpreted the presence of these tubes as a validation of the legitimacy of the child’s illness. Observation led me to question the ownership of these tubes as they are neither part of the child nor separate. Should they be treated with the same sensitivity to exposure as the child’s body and excretions direct from the body? The way drainage bags and naso-gastric tubes were handled seemed to affect the sense of well-being of the child and threaten dignity.

Staff were conscious of the boundaries of the child and their sensitivities to their bodies in relation to their age. They perceived covering up the body as central to the promotion of dignity. They recognized exposure to be seen or imagined, such as when others could
hear and imagine what was occurring. Some staff recognized that children had preferences over how they presented themselves in terms of dress and tried to accommodate their individuality where possible. They thought that some bodily functions were more embarrassing to talk about. Primarily they mentioned issues relating to girls rather than boys.

The bodies of the children were managed by staff, and so was their pain. Staff identified pain as sometimes being caused by medical interventions. Local analgesia was not given for all procedures because it was felt that more stress would be caused or thought that the child was too young. There was some evidence to suggest that the bodies of babies were conceived of differently from the older children, as if their embodied experience was qualitatively different.

Doctors and nurses were aware that they were powerful compared to children and their parents, but they rarely spoke in terms of power imbalance. Children were seen to try and exert some control over what happened in exchanges with staff. This included ‘opting out’ in some way. Staff talked about using force and coercion in undertaking procedures. The more junior nurses seemed to explain this through the principle of acting in the child’s best interest. The more senior nurses acknowledged an element in assault or use of power over another, this may have been due to them having moved away from day to day working on the ward and, or the experience of having children themselves.

"Best interests" could be used as a way of rationalizing something that no-one wanted to do, in particular inflicting pain on a child. Nevertheless in protecting the nurse or doctor, it could be a way of negating what was really happening to that child, at that moment.

Staff interpreted the demonstrations of babies through crying, screaming and wriggling as babies’ dislike being held down. Arguably the acceptance of causing pain may be difficult for staff to bear. Therefore interpreting a child’s screams as an objection to innocuous sounding 'holding down' could be used as a defence by staff, letting them believe that what they were doing was without controversy. I argue that the widespread idea that babies object not to the pain, but to 'holding down,' had become an institutional assumption.
The belief that babies cannot and do not communicate adequately supports the use of power over babies in a way that was rarely acknowledged and questioned. There was a presumption that "they cannot tell us that they do not like it so how can we know?"

An awareness of onlookers, or witnesses, was evident in what the staff had to say. There was a difference between legitimate witnesses such as the staff and family and 'others.' Prevention of exposure of children to these others was thought important in the promotion of dignity. The notion of privacy was equated to dignity by the nursing staff. Privacy was more easily operationalized and measured. Nevertheless, the need for constant surveillance compromised privacy. Children who had had long or numerous admissions became habituated to exposures and being witnessed.

I have described how staff sought to do or perform dignity. I have done this through using terminology from the stage and adopting a symbolic interactionist approach (3.5.4). The performance of dignity was constructed in the given environment of the hospital ward. Behaviours such as 'covering up' were understood to convey respect and to honour the dignity of another. Props, such as curtains, were used widely by the staff to signify a personal or private event, to protect the patient and the onlooker, and to contain. This meaning was largely shared and understood by staff and parents. Staff also spoke of rules, both implicit and explicit, that determined how dignity was managed.

As staff explored dignity as a concept, they acknowledged their own part in honouring the dignity of another. They spoke of their role in terms of emotions work. I identified four themes from their responses describing how they used their selves to understand others and to get the job done. These are: tuning in, moderating, detaching and integrating.

Some staff mentioned the stigmatizing nature of some conditions that identified those who fall short of the "gold standard" of the normal child. When discussing babies and dignity staff spoke about the extent babies had dignity and the need to limit their bodily exposure as any other child, even if they themselves were unaware. Staff held differing views on whether babies had dignity, however, they spoke of treating babies "as if" they had awareness. Babies seemed to have relative dignity and their value was, in part, dependent upon their construction of their value by their parents.
In the final part of this chapter I have discussed "humanness" and some of the reasons why a child may not be treated in a way that recognizes this humanness. The notion of humanness resonates closely to intrinsic dignity. Staff thought that they might become hardened to acknowledge the humanness of individual children, or they may become too preoccupied with the task, under personal stress, or that they did not have enough time to give this humanness due consideration. They described times when acknowledging the humanness of a child and dignity was not a priority, such as in an emergency. Dignity on the children's ward was not essential but desirable.

From the perspectives of the staff I will now continue, in Chapter Seven, to discuss the findings from the children and their parents.
Chapter Seven
Findings
Voices of the Children and Parents/Carers.

7.1 Introduction

I now turn to the findings from interviews and observations of the children and their parents. In the same way as the previous chapter, I have divided these findings into two parts. In Part I, I have presented and discussed data concerned with the context of the research, that is the total environment, from the impact of the layout to the impact of family centred care for the child and parents and the way children are constructed.

In Part II, I have drawn from the data findings that relate to the meaning and construction of dignity for these children on the ward.

It will become apparent that some, but not all the themes, are duplicated across the three findings chapters that represent the voices of the researcher, the staff and the children and their parents respectively. Finally I summarize the key findings of this chapter in preparation for my comparisons and arguments in Chapter Eight.

Part I Context

7.2 Environment

In this section I have clustered the environment and the strangeness of the context of the hospital ward and to create a sense of the total environment. Once again, I have found it useful to use the word "vibe" from my discussions with 3FHCA to describe the total atmosphere in which the children and their parents find themselves. The physical environment sets the context for life on the ward. Several of the children liked their surroundings and described a sense of comfort from the things around them:

"I think it (the ward) is really nice, because it is like a bedroom really. I think it's actually better than a bedroom because you've got your own 'phone. I think the colours are nice and the clock over there with animals, it's just nice. The colours make the room feel warm" (cf12030).

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She adds later: "I've got a proper duvet" (cf12030).

In contrast to any pain they might be experiencing, the children spoke about what they liked in hospital, including that which gave them physical comfort. For example a twelve year-old boy said:

"It's comfy, comfortable, the bed is comfortable and the people are nice" (cm12066).

And a fourteen year-old girl said: "It's really nice, it's quite nice." (cf14047). I noted that it was as if she modified her response after her initial enthusiasm. The three responses above are all from children who had come in for short stays and their appreciation of their environment may not be representative of those who stayed for longer.

Pictures drawn by the children were displayed on the walls of the bays, although they did not match the occupant of the bedscape. The environment was defined as a child-like place by the staff who put up the pictures. However, it did not allow the children to be able to personalize their immediate environment by choosing to display their art as an expression of themselves.

On the whole the children did not overtly make their bed space their own by displaying possessions. In the ward area, cm14010 was an exception by hanging up some of his clothes around the curtain rail as if using it as a washing line. It was almost as a sign of joy and re-establishing his out of hospital persona at his impending discharge home the following day.

7.2.1 Side rooms

Children and their families in side rooms were able to spread themselves out and fill their space. Cm6024 was in a side room and had his teddy and other toys, videos from home and his own pyjamas in an attempt to control his environment and take ownership of it, as well as keeping things as normal as possible and expressing his individuality.

Some areas were less liked than others, especially when they were full. There was a four bedded baby bay that was not always popular with the parents:
"Like this room, this Baby Unit, this little baby room, which they didn't used to have on X (the previous) ward. I don't think it's good for privacy, I don't think it's good for parents getting sleep, I don't think it's good for children sharing germs" (mcm17.12035).

This parent was critical of the Baby Unit not only for the lack of comfort and privacy of the parents, but also for the well-being of the children. This room was extremely warm in hot weather, with no air conditioning and windows that could be opened a very small amount.

7.2.2 Playroom

The Playroom was appreciated by the children. Several children, particularly those who were in for shorter stays, commented that it helped them not be bored. Parents thought that the Playroom was good, although more limited for the older children. This was echoed by cm6024, aged six, who described the Playroom:

"It's a bit nice, but they don't have many toys for big children in the Playroom."

Some of the younger children (cf3026) enjoyed dressing up and were able to immerse themselves in their games such as Sleeping Beauty. However play was restricted, for example on one busy day in the Playroom the father of three year old cf3027 called "Don't run around, that's all I ask." I was not sure whether he felt that his daughter may have or cause an accident, or that it was in some way unacceptable. Parents and supervised siblings were welcomed in the Playroom although they were not allowed to bring hot drinks in to protect the children and others from the possibility of burns.

7.3 Strangeness

Throughout my analysis of the fieldwork, I have found using the notion of strangeness useful as a tool, or conceptual device, to identify aspects of the field that warranted further investigation and explanation. Hospitals are strange places and, as a researcher, there was value in being able to try for a time to 'keep it strange'. The ethnographer
Toren (1996, p.102) advises ethnographers to "render strange what we take as given" as a way of questioning what researchers see before them (3.4.2).

It can be easy to disregard the quality of the field in qualitative research, by this I mean the essence of the field site, the atmosphere and the feelings that are aroused just by being there in that environment. I developed the construct of "strange" from my earlier pilot work (4.2.4), where I noted the impact of the alien hospital environment. The overwhelming quality that emerged for me was the strangeness of hospitals and the way people, especially children have to cope and adapt. Hospitals were and, despite huge changes in just seven years, are strange, they are out of the ordinary. Yet as a nurse researching in such an environment it could become possible to forget and to disregard this, and in so doing so, misrepresent the data.

My acknowledgement of strangeness gave me the opportunity to appreciate something of the alien nature of a hospital to a child entering, perhaps for the first time. I found it useful to tune in, rather than tune out to strange things around me as an ethnographic tool and attend to the unusual rather than to accommodate it as part of every day existence. In this way I could interpret and understand the meanings and norms of the ward culture. It has been the study of the strange things that enabled me to see the way staff, children and their parents worked to 'normalise' the strange, for example through the adoption of agreed rules (7.11.3). Strangeness seemed to have an effect upon the control and power relations within this setting. During the study, I examined the reactions and adaptations children experienced and expressed in this sometimes, alien environment and in turn how this influenced and affected their dignity. The strangeness and associated non-understanding of meaning could render children and their families and their researcher powerless. One mother, mcm2018, described how the hospital could be frightening for young children:

"So big and so many people and I think it's a bit scary. People in their uniforms and things."

The older children too seemed rather overwhelmed by their environment. Children in the bays had to leave the bay walk down the corridor, past other bays to the entrance of the Playroom. Despite expressing her appreciation of the Playroom and the toys in it, cf12030 admitted:
"I was too scared to go in there (Play room) a minute ago because I was all on my own."

Not to feel scared was deemed important by parents with a link made between things being strange and fear. Mcf15.12032 said:

"...not to feel scared that whatever is happening to them is demystified in whatever way is appropriate for the child so they are not afraid."

Nevertheless, as cm14039 summed up: "There is something about hospitals which isn't...which is slightly unnerving especially to children."

### 7.3.1 Strangers

In an age when children are taught to be wary of strangers for their own safety, children in hospital were expected to allow strangers access to their bodies and their feelings. The impact of the hospital is described thus by one mother:

"A lot of strangers doing things that only mummy normally does...like picking her up" (mcf3036).

When children were admitted through Accident and Emergency they were seen and examined by many different people on their progression to the ward:

"Everywhere I went to there were different nurses and doctors" (cf11087).

I was conscious of not becoming another stranger to demand access to the thoughts and feelings of the children and their parents and took time to make clear who I was and what I was on the ward to do.

### 7.3.2 Journeys

The focus of my study was the hospital ward, but the experience of the children and their families of that ward were affected by their journeys to and from the ward. Some of the oncology children and their families spoke of their frequent trips back to the hospital in the middle of the night if they developed a pyrexia that could indicate an infection:
“So a lot of the trips were in the middle of the night, which kind of adds to the trauma of it all somehow” (mcm4052).

The journey from the ward to the operating theatres was long and gave rise to comments from the children and their parents. Usually the children travelled on their beds to the operating theatre, dressed in the costume and accoutrements of a hospital patient. They were taken from the ward into the public space of the corridor, the lift, the corridor past the café where the public could sit and the shops and over to the private space of the operating theatres. As they travelled through the public spaces, accompanied by a parent and a member of staff in theatre robes, they attracted considerable attention. They and their accompanying parent were often anxious and in a vulnerable state. On their return the child was often not fully conscious, but the parent was often emotional and the child inevitably had an array of infusions and drains protruding from their bodies. In this fashion the child was paraded through the public spaces of the hospital. The child seemed to become a motif of the important work performed by the hospital. The propulsion from the relative private space into the public domain of the hospital thoroughfares could make a spectacle of the child, albeit unintentionally.

Some of the children spoke of their unease at being wheeled through the building, in this example likening the experience to a scene from a television drama:

“People just looking, giving you funny looks, ‘cos they were walking around...and you were going down to have an operation on a bed, it’s the sort of thing you see in Holby City” (cf14047).

She was conscious of being an object of interest for the passing people, an exhibit that attracted uninvited attention.

Cf11087 and her mother also spoke about the journey from the ward down to theatre:

M: “It was shame you had to be seen by Joe Public as well isn’t it?”
R: “Did you notice people?”
C: “Yeah, they were all looking down at me and everything.”
One mother (mcf12080) described how her child feared the smell of the hospital after so many years of admissions and operations. She described how her daughter reacts to the journey to the operating theatres:

"As we are approaching she can smell the anaesthetic, because she knows and she goes loopy."

Another mother (mcf14065) described the journey she and her husband took to theatre to collect her daughter and the panic she felt when she could not find the way:

"We’d keep stopping people and you could see they were ‘No, no we don’t know where theatres are’ – for God’s sake you’ve got my baby down there. I was tearing round and eventually I managed to make someone understand what was happening so they helped us!"

Later she reflected back to this moment saying:

"We just felt in control and all of a sudden lost it."

7.3.3 Making sense of strangeness

Earlier, in my reflections of my experiences as researcher, I commented on my feelings as an observer:

Not quite knowing what I should be doing and what is expected of me, feeling self conscious and not relaxed, but on show (21.04.05).

I wondered how much these feelings resonated with those of the parents and children. I continued in my observation record:

"There is a sense of being ‘in limbo’ among the parents and no doubt the children which in itself is dis-empowering. I feel it myself as an observer."

On arrival, the parents and children had to interpret a subculture with social rules at odds with the norms of outside (Warren et al, 2000). When the stay in hospital was prolonged then the children and their parents were forced to adapt and seemed to become habituated to the ward environment. Children and their parents were involved actively in the process of interpretation. As I commented in my observation record:
They become attuned to cues on the ward and they attribute meaning to them. For example the clatter of the lunch trolley and the smells coming from it, the voices of doctors gathering for a ward round (13.4.05).

This process was part of the transition of children and their families from what I termed 'just visiting' to 'living in' hospital (7.6.2). Even the youngest children learned quickly the meanings of cues and actions. From my observation record (13.07.05), I noted:

*Cm22.12053 has been in hospital two days. He already shies away from blue tops according to his mum "He knows everything at 22 months."

It was striking how the children made sense of and interpreted situations that were new to them. An eleven year-old girl described to me what happened when she had her anaesthetic:

"They just counted to ten and about five, my eyes shut and then my soul went out and I didn't feel anything and then 15 seconds later I woke up and I was in a different room and my parents were looking down at me" (cf11087).

I was struck by the powerful imagery she had used as if to relate her experience of being made unconscious as dying. She described her embodied self as separating into self (soul) and body as she lost consciousness and then a sense of reintegration as if just seconds had passed. She later described how she had been worried about being put to sleep because she thought it was going to hurt. This surprised me as I had imagined that her anxiety was precipitated by an interpretation of unconsciousness as almost a mini death.

As they became used to and habituated to their environment it was apparent that some of the children learned how to use the system for their own ends:

*Cm7011 makes no eye contact with me. He looks at the nurses and the doctors, he stands at the nurses' desk looking at the nurses because he knows that they can give him what he wants (21.04.05).

In this example, it seemed that cm7011 had learned to dismiss quickly those people on the ward, such as me, who were of no relevance to him.
On occasion the child appeared to appreciate the experience of being interviewed. I interviewed 4 year-old cm4052 with his mother at home. He seemed to enjoy talking about the times he spent in hospital. He seemed almost nostalgic, it was as though he found it comforting to make sense of what had happened with hindsight and in the safety of his home. Equally his mother said he loved going back to the ward now.

For the children and parents who experience long periods of hospitalization, the strange becomes the norm. The children and parents who were living in the hospital used the space differently from those who were just ‘visiting’. I recorded:

> It is noticeable how parents who have come into hospital before, make a greater use of the space, for example crossing the bay to get tissues for their child. The novice, (visiting) parents tend to stay in their own bed space (9.12.05).

These experienced parents were able to read cues from the staff that may have not been obvious to the newer parents. They were able to interpret situations as they unfolded. Mcf12080 described the way another, newer, mother was told some news following the results of tests on her son:

> “I knew that something wasn’t right when the doctor said to Mum, ‘Hello Mum, do you work?’ right. He said ‘Hello Mum, what shall I call you?’ to be fair. ‘I am Dr Bloggs’ and she says ‘Oh hello, my name is Mary’ and then he says ‘Do you work at all?’ and I just knew, because I have lived in the world for twelve years, if he’s going to be sent home after he’s T’d and Wee’d then you’re not really interested in what Mum does are you?”

This mother uses nursing terminology, “T’d and W’eed” is short hand for baseline observations and urine sample having been taken. Her familiarity from twelve years spent coming in and out of hospital with her daughter enabled Mcf12080 to infer from what and how the doctor began his discussion with the new mother. She realized before the new mother that serious news concerning the condition of her son was impending.

7.3.4 Familiarity

The children appreciated seeing the nurses that they already knew (6.3.3). This was particularly true for the children and their families who had had repeated admissions:
"It helps to have nurses I'm used to...I'm used to half the nurses here 'cos I've seen them loads of times and we get on well" (cm11046).

The children were pleased not to have to make new relationships on each visit and renegotiate care with strange people. Mcm8080 described how familiarity and continuity of staff were very important for a child who needs to come back frequently to hospital:

“So for him the familiar faces over a period of time has been very important and we have been lucky here 'cos they don't really suffer from a lot of agency nurses, they seem to have quite good continuity with their nursing so he has got to know, regard most of them as friends over the years.”

She continued:

“Familiarity of faces is really important as he trusts familiar faces and he understands that they understand where he is coming from.”

When asked how he would like his nurses to be, cm8080 replied: “nurses I know and smiley nurses.”

7.3.5 Reciprocity

I was curious about the relationship children wanted and needed from the staff. The children wanted familiar nurses and doctors, who smiled and “chatted to them” (cf12030). My sense was that they wanted safety, recognition and interest in themselves. I was less certain that they wanted reciprocity of a relationship as described by the nursing staff (6.5.1.1). My feeling was, that now their parents could be there with them, an intimate relationship was no longer needed with the staff.

Nurses described how they liked to see familiar patients and that they thought patients and their parents were glad to see them (6.3.3). The responses from the patients and their parents were somewhat tempered. This is described by mcm17.12035:

“But it's nice when you walk on the ward and people say 'Oh no you're here again!' because that is how we feel, one hundred times worse, but 'Yeah unbelievably we're here again'. You know for the last three weeks I have been here with him every day, that's tough you know, that's really tough you
know, even to be on the ward, or come and see the consultant, or see a physio, it’s tough, so when someone says ‘Oh God, you’re here again!’ ‘yeah it’s tough’ and it’s nice when they understand that ‘cos obviously we don’t want to be here, it’s not a nice..., you know they make it as nice as possible, but it’s not a nice place to come.”

7.3.6 Routines

Some of the children with special needs seemed more disturbed by the strangeness of the hospital and the different routines. One of the children with Asperger’s syndrome\(^8\) was especially sensitive and maintaining a sense of normality around him was paramount for his sense of well-being. His mother, mcm6024, was attuned to this and thought that maintaining a patient’s sense of normality was crucial. When asked what she understood by dignity she replied in the context of their admission through the “Out of Hours” service:

“It’s trying to maintain, in a hospital sense trying to maintain a sense of normality... It was quite freakishly abnormal to be sitting somewhere in his pyjamas... and he was asking me about brushing his teeth and having a shower, doing the normal things you do to make you feel life is normal.”

Mcm6024 continued to talk about the way his Asperger’s led him to react in a way that was out of the ordinary to treatments and procedures:

“It’s not been easy to treat him either ‘cos he really can’t stand unfamiliar tastes or textures of foods or medicines so Nurofen (Ibuprofen) can be very hard to give him even though it’s the best thing for him. Sometimes it’s a bit hard to treat him ‘cos he really really has almost a phobic reaction of certain procedures and things and it’s been really quite difficult, where he might really shout or scream while things are being done that hurt him. He seems to find it hard to control this kind of thing.”

Her comment demonstrated how even the “normal” first line treatments for pain and pyrexia such as Nurofen\(^\circledast\) (Ibuprofen) could be difficult to use when her son was ill.

Other parents commented on the importance of routines for their young children, in particular as an antidote to the strangeness of their environment. The need to keep to routines was linked to dignity and the way it was promoted in hospital mcm5016 said:

\(^8\) Asperger's syndrome is a form of autism and is a condition that affects the way the person communicates and relates to others (National Autistic Society, 2003).
"Keep to their routines, keep to the way they live their life as much as possible."

A sense of normality was thought to be important and by superimposing a structure of a normal routine the threat of strangeness could be diffused: "something sort of normal in the daily routine" (mcm6.52005).

It was as if the strangeness of the environment was threatening to the confidence of the children and provoking anxiety. The children and their parents described how they took comfort in the routines of the day:

"The regularity of things, the fact that staff keep coming up and doing various blood pressures and the rest of it...that signifies that somebody is keeping a watch" (mcf6042).

The children said they appreciated the routines (and emotional labour) of the nursing staff as they made them feel safe and contained and reassured:

"The nurses and everyone, they comfort you and they come in every two minutes and check on you and everything" (cf11087).

The children and their parents worked to learn and understand the meanings of the routines of the hospital ward. Their efforts to make sense of the strangeness of their environment was an attempt to contain anxiety and regain control of events and their surroundings. This adaptation to life in hospital marked a transition from, what I have termed 'visiting' to 'living in' the hospital.

7.4 Changes in the role of the children's nurse.

It was evident from this study that the children on the ward no longer received their day to day care from the nurses, instead the parents, primarily the mother undertake this role. This was a reflection of the changes that have taken place in the care of children in hospital in recent years and the corresponding change in the role of the children's nurse (6.3). Children appreciated parental presence. When asked what was really important for children in hospital cm8080 replied:
C: "Being looked after and being cared for."
R: "Who would you like to look after you?"
C: "Mummy and my daddy and my sister."

The children seemed to expect they would be looked after by their parents in hospital. They were unaware of past times when parents did not stay and they expected care to come from their parents/mothers. When I asked cm4052:

R: "Was that in a side room, a room by yourself?"
C: "No, I need Mum to help me in there."

Children with special needs were catered for in their day-to-day needs almost exclusively by their parent or carer. The mother of cm14066 said that children with special needs get "distressed" if their parent cannot be with them all the time. The nurses were not able to establish a relationship and to be with the child on a one to one basis in the way that was required. The nurses had to oversee the care of several children and prioritize clinical need. At the time of this discussion, cm14066 had had some teeth removed, and there was blood all around his mouth and he was still in his operation gown. Parents of children with special needs felt a requirement to be with their child all the time. There was some resistance of staff in being involved with the care of children with special needs (6.5.6). The parent, or carer, was acknowledged to be the expert in the care of their child in these cases. Nevertheless, cm14066 had not been an in-patient before and his mother was a novice in the hospital environment. It seemed that she could have appreciated more input from a nurse to tell her what she could do, for example, help her son get washed and changed following his operation, in preparation for going home.

7.4.1 The meaning of touch

Body care was done or overseen by the resident parent. This has led to nurses taking a step back in the intimate nature of caring such as washing and dressing and arguably comforting and holding. The touch of nurses has become associated increasingly with the "horrible bits" (6.3.2).
Awareness of child abuse in recent years has affected the way all carers and nurses in particular, look after children. The vulnerability of nurses to allegations prompted guidance to protect both child and professional (Royal College of Nursing, 1997). This has had repercussions for the way care of children is provided within an institution such as a hospital. Those working in the caring professions nurses, doctors and teachers are discouraged from using touch to communicate affection. This comes at a time when the role of the children's nurse has taken the nurse away from direct care of the children. I argue that the meaning of touch has changed alongside these developments and rather than the touch of the nurse being there to comfort, it is more commonly associated with a procedure. Indeed, some of the mothers (mcf15.12028) of babies reported that their child was fearful of people wearing blue t-shirts, the nurse uniform at the time of the study. In my interview with the parents of cf15.12032, the father commented:

F: "She's been handled nicely and they've always been very kind."
M: "She doesn't like them, but because she doesn't know what's going on."
R: "What does she do?"
M: "Screams fights."
F: "Pulls away."
M: "She will look at the nurses now with recognition and she will cry because she anticipates something is going to happen."

One of the more poignant differences from every day life for the children was the use of touch generally. The experience of touch is changed greatly for children in hospital. Whilst undertaking some comparative observations at a Day Nursery (4.3.3), I was struck by the way the children, in this case aged rising four, touched one another and their carers continually. When I mentioned this to the nursery supervisor she thought that the children chose to touch those they were most familiar with. It was the children that had been there the longest that would sit very close to her, or touch her. In hospitals, the whole meaning of touch is changed: the bodies of children were often touched and examined by strangers. Children in hospital are rarely able to take part in the constant touching and joining on to other children that I observed in the nursery. Children were often kept and treated at arm's length and touch can become associated with pain.

7.5 Health professional, parent, child triad.
There was recognition by the parents of the three-way nature of the patient-doctor relationship, to include the parent. The specialty of paediatrics was described as being:

“...so different, because the doctors and nurses are not just dealing with the child, but they are dealing with the child’s parents as well” (mcm4052).

7.5.1 Communication

An essential part of this, sometimes uneasy, partnership was communication. Children and their parents were clear about the way they would like to be communicated with. For example, parents appreciated staff introducing themselves to their child:

“I think its good that people introduce themselves and say who they are and ‘I’m going to be looking after you today’” (mcf6042).

Parents saw the effort staff made to communicate with their child as a way of demonstrating respect. The mother of a four-month-old twin who was in for investigations appreciated the way her baby girl had been cared for. She said:

“Even though they can’t speak for themselves at this stage, they are treated like people” (mcf4.12007).

It was as if good communication was key to a relationship that acknowledged the worth and shared humanity of both parties. Similarly the mother of a six-year-old boy said:

“They should be spoken to, not above or round” (mcm6052).

It was as if it was a basic human requirement to be acknowledged and spoken to (7.13). The children also appreciated the way staff spoke to them. In this case a consultant explained to a fourteen-year-old girl about her forthcoming operation:

“I was told what was going to happen quite a lot which helped, because I knew what they were going to do to me and they told me about the operation” (cf14047).

She also felt that she was able to ask questions.
Parents praised staff whom they thought were good communicators with their child. Mcm2020 described her child's consultant:

"He makes so much eye contact with L., he has just got a natural respect and mutual, you can just tell. When he is doing something like looking in his ear, he'll talk to him and it's not 'I'm doing a procedure here', it's a natural attitude."

Parents of even very young, pre-verbal children were adamant that their child was able to communicate at some level, if others were able and willing to listen and hear what they had to say:

"Children certainly let you know when they don't like something that's going on. It's a case of listening to them and realizing that's what they are trying to get across" (mcm6.52005).

The aunt of cf15.12028 explained about the way in which her fifteen-month old niece had been able to participate in her care:

"She's had a voice, hasn't she, even though she's not talking, she's made it clear."

Communication was seen as a two way process, not merely the staff imparting information in a way that could be understood. The ability of children to communicate effectively was upheld and the need for staff and parents to listen was emphasized.

"If your kid suddenly said 'no' to something, then that should be heard" (Mcm5016).

7.5.1.1 Reading between the lines

Non-verbal communication was also seen as important. Mcm5.12013 described the ways she thought children could pick up on what might be going on by the way adults behaved, especially when they were not being altogether truthful:

"I think they can pick up on your expressions, and the older, possibly the older they are the more they they've had experience of people lying to them and you know, 'This won't hurt a bit' and then you go on and really hurt them. I think sometimes you've got to, I don't know how you can't tell them it
won’t hurt at all because the next time you tell them they won’t believe you
and you have a problem on your hands. Yeah, I’m sure they pick up on
visual expressions and looks, you know whisperings.”

Parents thought that their children were discerning about the staff and whether they had
real concern for them and this was revealed in the way staff asked questions of the
children:

“…not just asking stock questions that are supposed to sort of break the ice
when they are not really interested in the answers. You can tell when people
do that, he (cm0879) can as well, he’s not stupid” (mcm0879).

Thus it was not merely what was said, but how the children were spoken to and
communicated with. Children and their parents were also sensitive to, and would
interpret, the body language and expressions of staff.

7.5.1.2 Leaving the child out

Some parents thought that children and their level of understanding were not always
considered when staff spoke.

“I think some doctors can assume your child doesn’t understand, so they
don’t bother trying to explain” (Mcf2020).

The presence of the parent meant the staff could be seduced into talking with the
parents in preference to the child, even when they were teenagers. This was highlighted
by the mother of a fourteen year old who had been in hospital for eleven weeks, on this
occasion:

“I think the temptation is that is if you are here as a parent, that the patient is
actually ignored.”

To her son she continued:

“Even at your age, at fourteen, I think one of the difficulties that we’ve had,
is that they forget that he is here and that he is able to answer his own
questions about his own condition” (mcm14010).
Situations could be made more bearable if routines and events were explained to children and their parents. Cf11087 was waiting for her appendix to be removed. She saw several people go down to theatres before her, some because they were emergencies and others because they were "booked". The system of having different specialist surgeons for different conditions was not explained and the girl and her mother were upset at being seemingly overlooked. The need to explain and assess the impact of the information on the child was seen as important. As Mcm5016 suggested:

"Try to respect when they do seem unsure about things, or are scared about things and try to take time to explain things to them, go through worries with them before they have to go and do some sort of procedure, rather than just picking up and saying 'Right off we go for your operation.'"

When staff did take time to explain and to listen to the concerns of the children, their efforts were greatly appreciated. I noted in my observation record (5.8.05) the experience of a twelve-year old boy:

*Cm12066 has had an operation on his foot. He was very appreciative of the anaesthetist who had spent time allaying his fears about 'being frozen in his body', unable to move, but being able to feel everything after seeing a television programme. The anaesthetist had not lied, but taken the time to say that it had happened in the past but not here and went through the ways that the anaesthetist can ensure that the patient is unconscious.*

Certain children had particular problems in being heard and their needs understood. Sometimes there was a presumption that these children were unable to communicate, for example babies:

"He can't complain because he is too small" (Mcm17.12035).

This was also the case for children with special needs including those with complex health needs. Cf8050 had special needs and did not speak, instead she communicated through mimes.

*She mimes something to me with a pen as she paints. I try to understand what she means. I get it wrong and she responds by looking very cross and stamping a foot. I try about three times. At the back of my mind I wonder what she will do when she gets really frustrated with me. (I imagine that it could be at this point I might choose to not understand and withdraw)*
However on the fourth attempt I realize that she is asking me to write her name. I check her name band for the correct spelling and put it at the top of the picture. She is very pleased and runs back to show her Mum (10.0.05).

The staff, with busy workloads may well not have had the time necessary to interpret the mimes of this little girl. I could see how they would depend on the mother to translate for them. Nevertheless, I have used this section from my notes again because understanding her gave me a rewarding feeling of connection (5.3.6). I wondered if this was the sort of rewarding experience described earlier (6.3.3) that staff, who had been working as children's nurses for many years, felt that they had lost.

7.5.2 Role of the parent

The parents recognized the important link they could provide between child and health care professional. For example, one mother talked about explaining what the doctor said about ongoing therapy in a way that would be most acceptable for her child:

"Interpreting what he (the doctor) says. You know your child and you know what will make them most anxious, what they can deal with, and what they can't deal with and being able to help the child communicate" (Mcm0879).

The quote above demonstrates how this mother acted as an interpreter for her child both in terms of translating language, but also in couching the information in appropriate way.

7.5.2.1 Advocate

Parents described their role as being an advocate for their child. Below are responses from three parents whose children had been in hospital for short episodes of care or for investigations. They spoke of how they felt they had had to protect their child in response to the power of the professionals and the vulnerability of their child:

"You have to stick up for your kid don't you, if you are a parent" (mcm5016).

"Most important is protecting your child, I mean if a doctor came in here, trying to examine...without the curtains round I would stop and...because my instincts are to protect my child" (mcf12006).
"I suppose you are watching out for the welfare of your child, so you are your child's voice in a way and if something is not going as you would wish, it's up to you to say something" (mcf4.12007).

They described a defensive stance against their perceived threat of the staff and a sense that their child, if alone, would be unable to protect themselves.

7.5.2.2 Passivity

There seemed to be some ambiguity, at an institutional level, about whether the parents should be there with their child or not. This increased feelings of powerlessness. No food was provided for resident parents and they had to go off the ward to buy food. Food was not available even to those who were breastfeeding. One mother who at the time was breastfeeding twins (mcf4.12007) explained:

"I have to leave both the twins completely unattended and go downstairs to get a meal"

Mcf6042 commented:

"There's a parent room which is a bit ... pathetic, it's a bit small and um hot meals, it's all very cold by the time... You are not sure where you belong really" (mcf6042).

Some parents spoke of times, particularly at the beginning of their child's illness, when they felt dis-empowered and were unable to advocate for their child. Mcf20.12019 reflected on her early experiences of her baby daughter unwell in hospital:

"I was obviously very anxious, I just assumed that they knew what they were doing and what they were doing was right."

She describes a trusting passivity brought about by the anxiety she felt about her daughter's condition. She relinquished her role of caring for her child and entrusted it to the health professionals whom she thought knew best.

Another mother spoke of her relief at relinquishing control when her son was admitted:
"I mean that's a relief for me, because I have struggled to control his condition for a couple of days at home on my own and it was really too much to be honest" (mcm6024).

In a similar way Mcm2021 described how the shock of the diagnosis left her unable to:

"...start analyzing how you feel about your dealings with the staff you know, we were scared of upsetting them, you know, a lot of the time we let things ride."

The shock and feelings of being out of control of their child's condition meant that they were forced to trust the staff and their need to trust prevented them, at times from challenging staff.

7.5.2.3 Anger

When treatment did not go to plan or they, and their children, were not dealt with as they would have liked, the parents felt angry. It was this anger that, for many, fueled their assertiveness. Some of the respondents obviously resented this:

"In hospital it's almost a constant battle to get things done the way you think is the right thing, is the right way. But you often feel why the hell should we? Why should we have to do this? Why isn't this thought about by everyone who looks after them?" (mcf2020).

It seemed that parents often took on the role as advocate in desperation rather than choice. Mcm17.12035 described how her son had had to have cannulae re-sited:

"In the end, we're the one's that have taken a decision, if any decision has been taken at all, regarding whether this should continue and we're the one's that have had to step in and be protective."

She continued to describe one incident, at around midnight, when the doctor was trying to re-site an intravenous line. She said:

"'OK we need to stop now!' because, you know, when otherwise would we call it a day... 'If you were doing this to me, I would tell you to sod off, it's hurting, it's time to stop, you need to do something else!'"

She continued:
"I'm pretty hard, I'm robust enough, I'll put him through a lot of stuff before I say 'no' and suddenly, two weeks ago, I think no sleep, seeing him in pain, I just 'Right, OK stop. There's got to be a plan B, or there isn't a plan B? 'Don't be silly of course there is' 'You know, what would happen if you couldn't find a vein? You'd have to think of something else!'"

7.5.3 “Good” parents

Parents and children who were new to the hospital often tried to be 'good'. As a researcher, they were keen to answer my questions and I had to be careful not to abuse this. I recorded in my observation notes of 7.12.05:

Cm5.12085 is in for a blood test. I talk briefly to his Mum as they wait in Ambulatory Care. "I will be a good patient and wait" she said, a bit tongue in cheek. "Is that what good patients do?" I asked her, to which she replied: "Oh yes, they are patient and wait."

Sometimes parents were not always able to be good parents. For example when parents were unable to make themselves available when the doctors required it, they became frustrated at the limited communication they had with the staff. In my observation record I commented on mcf14.12045 who worked and could not always stay with her child. In her absence her child’s nanny stayed.

It must seem particularly important to communicate effectively with the doctors when you can if unable to stay with your child. The mother of cf14.12045 chats to me after the ward round ‘It’s a shambles’ she says. She has just finished a shift and must go and sleep. There is no-one for her to talk to (10.6.05).

Another parent, who had been resident with her child for several weeks spoke about how she planned to register a complaint against nursing staff but not until she was sure that there would be no comeback:

The mother of cm6.52005 is telling me about the few days they have just spent at a different hospital. The nurses were ‘awful’ but the doctors were ‘lovely’. She wants to put in a complaint, but she knows she has to go back and she wants to keep them sweet, ‘keep on their good side’ (15.07.05).
She described a dilemma in how best to obtain the appropriate care for her child. If she risked complaining then she might alienate the doctors who she saw as 'lovely.' This way of splitting good from bad when talking was not uncommon during interviews. It was as if participants found it easier to label one thing as completely 'bad' in order to protect another as solely 'good.' Splitting is a psychoanalytic term used to describe a defence against contradictory feelings about another, or as in this case the others, the health professionals (Jacobs, 1988). Idealization of one group, the doctors, was countered by the association of negative feelings with the nurses. Thus all the hostile feelings harboured towards the staff were attributed to the nurses. I speculated that this mother's representation of events could be a way of her dealing with a stressful time.

7.5.3.1 The “difficult” label

The parent/health professional alliance could be difficult to negotiate. It seemed, from my discussions with parents, a fragile balance to reach where the parent was sufficiently assertive and enabled to speak up for her child and family and did not fear being alienated and labeled ‘difficult' by staff. Mcm17.12035 described this tension by emphasizing the unequal nature of the relationship:

“For a person who is coming for the first time, it's a fairly alien and intimidating environment and to sit and say ‘well, I'd rather not sit and talk about this here doctor' whereas actually the main thing on your mind is really 'What can you do to help us?' You certainly don’t want to start by being confrontational.”

As time passed parents may still hold back from complaining or asserting their opinions. As Mcm2021 explained:

“We were scared of upsetting them you know. A lot of the time we let things ride because we thought well maybe there’s a bigger battle around the corner, or we don’t want to alienate them.”

Similarly mcf15.12028 said:

“You don’t want to hack anyone off because you don’t want to get a reputation.”
Families were isolated from one another, on the whole, during their experience of having a hospitalized child. Any interaction between children and their parents and others on the ward was dependent upon their own instigation. Isolation may have contributed to their restraint in speaking out. One respondent, who had made a complaint about a doctor she met with her daughter in Out Patients, said:

“So I did moan, but apparently I wasn’t the first, that made me feel better, that I wasn’t the awkward mother from hell” (mcf12080).

She seemed to have felt justified because she was not the only person to complain.

Parents reported feeling judged in other ways. One mother, mcm2018, described how she felt judged and told off by staff when she was asked to hold her child still for a cannula to be sited:

“‘Hold her still, don’t let her move!’”, like she was a prisoner, horrible it was sticking this thing on her hand. She was only 20 months. It’s as if to say ‘can’t you control your child? Keep her still.’ They are so frightened anyway!”

7.5.4 Parental presence

There was a lack of recognition by staff of the knowledge and expertise held by the parents, a phenomenon highlighted in the research of Callery (1997). In his qualitative study based on a children’s surgical ward, Callery describes how mothers found it difficult to convince staff of their expertise in their assessment of their children. I found that this undermining of a parent’s understanding of their child increased tensions between parents and staff:

“I think parents get pushed away by nurses up there. When your child is admitted to hospital, they sort of work around you as if you are not there, like you’re invisible” (mcm2018).

This was particularly so for children who had had long or frequent hospitalizations and this led to frustration and anger in parents:

“I had this one young nurse, young man, who insisted on administering L’s medication that we’d been doing for weeks and he said ‘No, no it’s me, I
have to do it.' And we said ‘No, we’ve been doing it’...He tried to shove it all in in one go, 5 mls, on a 5 month old baby and it just went spilling out all over everything...That was it and we just said ‘You have just lost half a dose, can you go and get some more?’ and he said ‘Oh no, he did get most of it’ and we said ‘no he didn’t, most of it went on the bedclothes!’” (mcm2021).

Parents thought that they were able to give continuity to the care of their child and by being present meant that they were able to monitor and keep up to date with what was happening:

"...you've got the full picture ‘cos you've been there" (mcf6042).

Parents thought that their presence was necessary as they knew the child best:

“You know your kid. You know the best approach to take. You know the things they are going to be hung up about” (mcm5016).

This knowledge of one another could also create difficulties. Sometimes, parents reported, children were more likely to do things when asked by a health professional than by their parent:

“Children are very good at playing up parents, they know which buttons to press, whereas if you are going in in a professional capacity it doesn't work” (mcf6042).

Children liked having their parent with them. In answer to my questions about what was most important for a child in hospital most mentioned parental presence, whether their mother was sitting there or not! They felt one of the things that was very important in hospital was to “have someone with them" (cm12088). Cf14065 described why she thought that it was important to have a parent there in hospital:

“It's much better to have parents with you so you can talk and to have the nurses be completely honest with you, so they don’t lie to make it better.”

She said this in such a way as to suggest that she thought nurses might not always be truthful with her. She seemed to value her mother as the conduit for information in the same way as the staff and parents did. Fourteen year-old cm14010 spoke about his
difficulties in talking with the doctors and how he appreciated his mother being there for when the doctors came around:

"It's difficult to ask questions and it's difficult to ask what to them because normally it's like 'How are you? We're just going to do this to you know', like I don't even know what's going on about here! ...They just go 'Hi, how are you today?' then 'Right, (mother's name), right Mum...' They just do this, I feel I'm being cut out of the picture" (7.5.1.2).

On occasion it was not the parent in hospital with the child, but a grandparent or carer, such as the child's nanny. I asked one carer what she thought her role to be when accompanying cf8069 to hospital on one of her frequent visits:

"I would bring her as they (her parents) would and talk to whoever I need to talk to and then refer back to the parents on whatever has been discussed."

This carer thought her position was to be 'as a parent' on the ward, but to refer back to the parents with regard to treatments.

7.5.4.1 Protection

When asked what role parents had in promoting the dignity of their child, mcm6048 replied:

"You can only really protect your child by being here, so you can make sure things are done in a way that you would like them to be done or that your child would like them to be done."

Later she said:

"You like to think that the medical profession would protect their dignity if you weren't able to stay. I'm sure they would but you can only be confident that that's going to happen if you are there."

It was as if this mother had a suspicion that best quality care could only be guaranteed if she was there, almost as a constant reminder to staff. Likewise, mcf14.52004 commented:
"Being here most of the time here helps, you can protect her from certain things."

Some children were quite active in their own defence. For example, cm6024, when he was feeling better, greeted visitors to his room in a particular way. When I asked him about the doctors and nurses coming round to see him he said:

“I’ve attacked them with that light saber and squirted some of them!”

Even the very young could put up a resistance Mcf15.12032 said:

“She will look at the nurses now with recognition and she will cry because she anticipates something is going to happen.”

This was following a lumbar puncture the previous day:

“She was battling about being restrained against her will.”

7.5.4.2 Change in family dynamics

During illness and hospital admission, parent and child spent more time together. Some respondents found this an opportunity to improve relationships:

“Me and my Mum used to argue all the time...after my operation she seems really closer to me” (Cf12030).

As well as a negotiation of relationships with the staff there existed a renegotiation of family relationships. Mcf6042 described the fluctuating need for dependence and independence for her six year old daughter:

“Sometimes, like when I have been here, she’s not wanted me, she’s wanted her independence...Where there was this other child, she sort of wanted to be her own independent person again.”

She continued:

“Sometimes you feel a bit sort of unnecessary here and then when she’s had her medicine, then there’s nothing better than having your Mum.”
Six year-old mc6024 was clear about wanting his parents to stay with him saying: “I’m not old enough to be alone”. We would not expect a child to be ‘alone’ in any other environment and so why in hospital? He thought that he would need to be 18 or 19 before he wouldn’t need his Mum or Dad staying. When asked what was good about having them stay he said “They are sometimes my entertainment” - a way of alleviating boredom.

7.5.4.3 Disciplining children

Parents and their children were constantly ‘on show’ on the ward and were conscious of how they might be perceived by others (witnesses). The disciplining of children was public. Darbyshire (1992) discusses the concept of “parenting in public.” I recorded this observation of public parenting in my observation record (21.04.05):

The mother (mcm5016) instigated ‘the naughty chair” as her son had continued to throw a ball around after she had told him to stop. He had to sit on the chair for 12 minutes in the Playroom. I wondered whether she was trying to humiliate him in front of an audience and show her control over him. Later I wondered if this was an expression of her own feelings of vulnerability and fragility.

On other occasions it could be the sibling who was the recipient of the parent stress in the way that they were disciplined:

The mother of cf4058 is telling her brother off for blowing bubbles in his drink. The mother seems quite stressed (15.07.05).

The alien nature of the environment and the anxiety of the parents were compounded by the presence of others and this could lead to a difference in the way parents related to their children.

7.5.5 “Wrong footing”

On occasion staff seemed to try to belittle parents by their interviewing style. It was easy for staff to undermine parents intentionally or unintentionally when they were newly arrived on the ward. Littlewood (1991) describes the intentional humiliation of nursing
staff as a "tactic of control." I made these notes while observing in the very public space of Ambulatory Care. Here the doctor was undermining the parent in quite a subtle way yet simultaneously demonstrating warmth to the child. Such a mixed message I termed "wrong footing". The mother was not able to react to defend herself because the doctor was showing kindness to the child, and thus she was kept subordinate.

There is a little boy being assessed. He is coughing as if he has a tickly cough. He was in 14 days ago and has come back referred by his GP (General Practitioner). His mother does not seem unduly worried. "How do you feel?" asks the doctor. I am not sure if this is directed at the child or mother. "He seems quite happy, but he is coughing a lot" says his mum. "When did he last have his inhaler?" asks the doctor in a slightly aggressive tone with the mother even though she is very nice to the child (as if it is not his fault he is ill, or that he has a mother who is worrying unnecessarily, wasting her time, not understanding what she should be doing about medication, giving an unclear history). It is as though the doctor is trying to intimidate her. It was as if because she demonstrated kindness and politeness to the child, the mother could not have any complaint in the way the doctor had dealt with her (9.12.05).

The actions of this doctor appeared to me to be a way of establishing power in the form of expert power over the child and the mother. I have reported this as an isolated incident, yet it nevertheless demonstrates the impact subtle behaviours can have in disempowering parents, intentionally or not.

7.5.6 Adapting to the system

Some of the more experienced parents described ways of working the system and of assuming power themselves. Some spoke of "ways of dealing with" the staff that they found helped them to get themselves heard and their needs and, or the needs of their child, met in the way they wanted. One mother (mcm2021) spoke of how she had tried without effect to get a scan for her son that she thought he needed. She then described what happened when this failed:

"The first thing that happened was that my husband turned up in his suit and after work attitude."

Exasperated at failing to get what she thought her child needed, this mother called on the father for assistance. It is interesting to note that he prepared himself by presenting
himself outwardly in a suit, as evidence of an occupation of seriousness and seniority. He also prepared himself inwardly (emotional work) to conjure up and use his feelings, such as those he experienced after work, to confront the medical team. In these two ways he was able to convey an impression of someone not to be dismissed. The child had his scan.

Another mother of a child with complex needs said:

"They are a bit forewarned about me up there...so I guess it's like 'Oh God,...X.'s here!' Because I will always fight for her, whereas they would take advantage of a lot of people and they just remember. It does seem that they try to remember their ps and qs when I am there, which isn't actually fair because they should do it with everyone" (mcf12080).

She went on to describe how they saw their child's consultant privately wherever possible and paid for her daughter's care (cf12080).

"Where possible we see him privately, 'cos I have learned over the years that (child's name) and her frailty and the NHS don't mix."

It seemed that despite her struggle on behalf of her child, there were times when she felt defeated by the system. The only way that she could get the care she felt her daughter needed was to pay for treatment privately.

7.5.6.1 Cynicism

It was noticeable from the interviews that the parents of those children who have had long and or frequent hospital visits spoke with cynicism:

"There are a lot of wet blankets who think nursing will sort have a better personality and it really doesn't. You know because everyone will think I am Florence Nightingale and you actually want to give them a big slap. 'Don't waste my time love, just get out'" (mcf12080).

In my observation notes of 25.05.05 I recorded that I saw mcm6.52005 in the corridor:

The doctors are starting their ward round I ask her if she feels she has to get in position when she sees them, standing by the bed present and correct. She said that she used to feel like that, but "not anymore", with a wry smile.
The children too got cynical about their encounters with staff. One mother explained how her son judged doctors coming in to see him:

"Not just asking stock questions that are supposed to sort of break the ice, when they are not really interested in the answers. You can tell when people do that" (mcm8079).

It was as if the imperative to "be good" (7.5.3) had dissipated, replaced with a need for honest and frank communication.

7.6 Construction of the child

This section concerns the way children were constructed on the ward and in what sense their illness and hospitalization reconstructs them from well to a sick child, from the perspective of the child and his or her parent. I was interested in how children were constructed differently when they were ill. I wondered whether any associated vulnerability in some way took away the import of the child's subjective bodily experience. This was most noticeable in the way the children who have long standing health problems.

7.6.1 Construction of the child as 'my child'

When talking to the parents it was obvious that, first and foremost, the child was 'their child'. They described concepts of ownership and of constructing the character of their child. Parents said:

"You know your kid. You know what approach to take, you know the things they are going to be hung up about" (mcm5016).

Parents interpreted behaviours of their children and defined characteristics of their personalities:

"She is a very feisty character and she is very attention seeking" (mcf15.12028).
Their own sense of dignity seemed related, or even inseparable to that of their child. For example, bodily exposure of a child could create embarrassment and unease for the parent even when the child was unaware. Mcf21.12019 talked about leaving her child to go to the canteen:

"I had left her in their care, without me there. When I came back, it was about midnight, and she was half dressed and I thought it was very undignified, but an insult to me."

7.6.2 Long term and acute stay

The children interviewed had had differing experiences of hospitalization. Some were on the ward for an overnight stay following an operation or procedure, for example for a tonsillectomy. Children who were having ‘routine procedures’ were generally treated in a routine way with care given through standard care plans. They were “visitors” to the ward. At the other end of the spectrum, were children who had had repeated or lengthy hospital admissions and were “living in” the ward. Cm14010 had been in hospital the longest at the time of the fieldwork, eleven weeks at the time of his interview. For such children, childhood had been characterized by a considerable time spent in hospital and or unwell.

There was a sense, from some of the parents of children with chronic and complex health needs, of them (those in for short stays) and us, the families of those with more serious and chronic health needs (cm14010, mcm14010 and mcf12080). I noted in my observation record:

*It must be hard for those who are staying to see other children going home after a brief visit when they know their road is a long one. It must be as if they are playing at being ill* (10.06.05).

The children in the main site were not defined by their medical condition. This maintained confidentiality and recognized the children as individual children. This was in contrast to the way the child patients were perceived in at Pilot Site (4.2.9). For example a child was referred to by one of the Health Care Assistants as “the infected eczema.”

7.6.3 Favourites

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The notion of favourites was developed from the Pilot Work (4.2.12). There was less apparent favouring of individual children on the ward of the main study. The most important factor for this was likely to be the greater presence of a resident parent. The opportunity for one child to become the ward's "pet" was taken away as the parent assumed the role of the main care-giver. Stockwell (1972) examines the notion patient popularity, in particular she explores the characteristic of the 'unpopular patient.' Characteristics she identifies as making a patient unpopular include being a 'foreigner, having been in hospital for three months or more, having a physical defect and having a 'psychiatric disorder'. She also identifies some of the attitudes and behaviours displayed by nursing staff in relation to these patients and how they enjoyed caring for some patients more than others. Although she lists attributes of the popular patient such as 'being able to laugh and joke' with the nurses, these are not always applicable to ill children. Nevertheless there is a theme of reciprocity, that the relationship was not all one way, that does persist to this study (6.5.1.1). Nurses in the Main Study described how they enjoyed closer relationships with the children and families who were long stay or frequent attenders.

Nevertheless, some children and their families seemed to be liked more than others. Children whose conditions necessitated more frequent admissions and were well liked, were greeted enthusiastically. I wondered what this was like for those children and their families who were not greeted in this way. New children were not always even acknowledged when they arrived on the ward. Stockwell (1972) sees ignoring behaviours as a deterrent to unacceptable behaviour such as demanding attention when others needed it. I was rarely acknowledged by staff as I came on to the ward during the course of the fieldwork and this gave me a sense of uncertainty and discomfort. I speculated that children and their families would want to be met and welcomed and their uncertainties about where to go and who to talk to managed.

Some children were very appealing to look at and responsive to the staff. This caused me to consider what it was like for those who are less appealing and responsive and what meaning this had for the child. I recorded in my observation record:
A baby (cf14.12004) is off to have a hair wash after glue was put on her hair for an EEG. She is being carried as if sitting on a chair, facing forward, by her dad. She is very appealing, the nurses laugh and smile and talk to her as she goes past. She smiles back (13.04.05).

I wondered how a sense of being liked or being a favourite, or not affects the child and their feelings of self worth and dignity.

7.6.4 “Gold standard” of the “normal child”

The testing and monitoring of children begins before birth to establish whether a child is 'normal'. One mother described how she, and her husband, learned that their child had problems at her twenty week scan:

“At her twenty week scan they didn’t know whether she had a stomach at all and then they managed to find out that she did have one, but it was on the wrong side. We knew she could have other problems associated with that, but that they wouldn’t be able to tell that till she was born. So when she was born she had lots of tests done and then we found out everything else” (mcf14.52004).

Other parents found out after the birth of their child that there were problems. I interviewed the parents of a seventeen month old boy (pcm17.12035) and they told me of their anguish of having a child with a variety of problems for which a range of tests and procedures had been done. Thomlinson (2002, p. 542) in her phenomenological study of the experiences of twelve families, describes the investigations undertaken on children classed as ‘failing to thrive’ and states:

“In an effort to find a diagnosis, these children went through many, often painful, sometimes invasive tests.”

The mother of cm17.12035 explained to me that it all started the day her son was born:

“We were about to be checked out, the normal sort of Paediatric check out and um they noticed that there were various things wrong. We had an SHO come in and do it and she went out and spoke to the Registrar...he came in a bit later and said ‘Oh I believe you’re worried about Downs’ um and we said ‘Well, oh my God no, but we are now!’”
Unfortunately, the Registrar had come to the discussion thinking that there were already some parental concerns about their child. The parents had to adjust quickly to abnormality as a possibility, and then as an actuality within moments. Mcm17.12035 went on to explain that:

"The Registrar looked him over and came up with a different host of problems from the ones the SHO had."

These new parents had been prepared to go home with what, they assumed, was a normal baby and yet was deemed abnormal following a routine pre discharge examination. Up until that point the parents had not suspected something was wrong which made the throw away comment of the Registrar devastating.

7.6.5 Age

Children defined themselves frequently by age with the older children feeling different from the younger children. A fourteen-year-old girl found it strange “being round smaller kids a lot of the time”(cf14047). The range of ages on the ward could sometimes cause difficulties when the needs of one child were seen to take precedence over the other. One fourteen-year-old boy described how he felt the needs of younger children were given priority over him:

"The expectation for a teenager is that always to give in to the little ones, so if the little ones are awake at half past five, quarter to six in the morning, then you actually find that it’s alright they bounce off the walls and run round very early on...when the lights go out, and you’re talking twenty to seven to seven o’clock at night. What happens to the older ones?” (mcm14010).

This comment seemed to conflict with what was said by the mother of a five year old (mcm5016):

“You might have a baby, or a two-year-old on the ward with like a thirteen-year-old so bedtimes and that kind of thing are gonna be out of the window...It’s strange enough being in hospital as it is apart from the fact that you have to stay up to 9 o’clock because that’s when they turn the lights off."

The fourteen year old (mcm14010) went on to explain that the situation was no better in the morning:
“Since I’ve been here, the parents across have been complaining that the TV has been on too loud, when it’s only been on ‘1’, the volume and I can’t even hear it. The time they wake up in the morning, you hear screaming, running out the doors. Doors closing, doors opening...that’s unfair because you know, I had to be quiet so that they could get to sleep, they’ve just woken me up, I can’t get back to sleep” (cm14010).

Mcm14010 suggested that toddlers were given preference over teenagers because:

"It’s easier to say to a teenager ‘you can’t have, you can’t do...’ than it is trying to argue with a toddler"

Chronological age was seen as not the only determinant when considering how much they understood of their illness and treatment. It was recognized by parents that some children had acquired considerable knowledge about their condition and that communication with them needed to be adjusted as acknowledgment of this:

“Some children are more mature than others and you have to find the right sort of level that they are comfortable talking with” (mcm8079).

For children who have experienced ill health over a long period, recognition of their maturation meant that the way they are spoken to, and with, needed to change. The mother of four year old cm4052 talked about taking blood from the portocath he had aged two and half:

M: “And what did she used to do to Wiggly? She used to give him something to drink didn’t she and then we take out some ketchup” (laughs).
C: “Silly.”
M: “Ketchup out and...”
C: “It was blood Mum.”
M: “Oh sorry, was it (child’s name)? We called it ketchup at the time!”

7.6.6 Gender

The children were in mixed bays. The majority of the nurses were female. There were two male nurses during the period of the fieldwork, but both had left by the end. This meant that any intimate care, if not done by the parent, was undertaken by female nurses. The older girls enjoyed good relationships with the nurses and appreciated
chatting to them. Some of the older boys expressed embarrassment at having procedures done by female nurses not much older than themselves. One (cm14010) described his unease at having swabs taken from his groin, on the ward:

"When you get older and you got female nurses looking after you, trying to get a sample or something, a swab, it just gets to you... 'Cos when they told me that it was a swab from the groin, I just thought they were having a laugh!"

By having a female nurse take the swab, his sexuality and feelings of embarrassment were denied and his protestations implicitly overridden by the nurse. The apparent denial of a potentially embarrassing situation, for both nurse and patient, and the adoption of a matter of fact manner may have been a concerted attempt to manage embarrassment. Lawler (1991) calls such tactics 'minfisms' which, she argues, are used to deliberately minimize the significance of an event. There is little research regarding the nurses and sexuality of children in hospital. The Royal College of Nursing (1997) outlines guidance to nurses working with children with particular regard to the intimate nature of many nursing interventions. Although the report states that some children may prefer a female carer and that this should be respected, it makes no acknowledgment of some children preferring a male carer.

7.6.7 Children with special needs

Despite not being told the diagnosis of the children, I was usually made aware if a child had learning difficulties as I noted in my observation record.

_There is a little boy with Asperger's in. I am usually told if a child has a SLD (Specific Learning Difficulties) whereas other medical diagnoses are kept confidential. I am told he does not want to be disturbed. There is a sense of nurses creeping round him for fear of upsetting him. However this leaves him at risk of being ignored (7.10.05)._

Staff relied heavily on parents when a child with learning difficulties was admitted. However their different needs did not always create additional problems. The mother of a child with Downs Syndrome explained how the journey to theatre, with the potential to cause distress to her daughter was enjoyable for her son. I noted in my observation record:
21.07.05 The mother of cm14066, who has a learning difficulty, says the journey to theatre is peculiar going past the eating area. She says that older children such as her daughter would be acutely embarrassed. "He doesn't mind, he was sitting up smiling and waving with his mouth full of blood."

7.6.8 Children as social beings.

During the pilot work in the nursery, school and hospice I noticed the sociability of the children as they constantly communicated and engaged with others. In the hospital ward, children were not routinely introduced to the children in beds adjacent to them. Generally the children were kept very separate. A considerable part of the day was spent on their beds or in their bed space, including eating their meals at their beds. The only area where they mixed was in the Playroom. Occasionally activities were organized for children in the Playroom. Children played together at the table football, but in few other areas. Televisions were generally watched alone or with family members. School was delivered primarily on a one to one basis during the period of fieldwork, although there was provision for more than one child to be taught at any one time.

Children who were in hospital for longer periods of time did make friends and were keen to do so, particularly to make friends with children who were staying in for longer periods of time. These friendships were not always recognized by staff, no doubt because the majority of the children were not in long enough to establish relationships. One boy cm14010 described how, on his return from another hospital, he was upset to find that his friend was no longer in:

"An old friend in a bed, ...when I came back from... I was worried and fed up that he wasn't there to talk to and that, you've got to get used to different people."

His mother added:

"Nobody picked up on his personal feelings, nobody approached him, nobody asked him what was wrong. It was just documented that he was incredibly unhappy at being back here."
One mother (mcf4015) described how she and her daughter had got to know another child on her last admission. He was rushed to the Intensive Care Unit in the middle of the night but they were never told what had happened to them and when they asked, they were told that it was confidential. The mother described how she felt these relationships forged in hospital were negated by staff and seen as temporary, relevant only while they were in-patients.

Nevertheless the irrepressible ability of the children to engage with other children they did not know during their hospital stay was noted by some parents:

"But children just connect, they just engage" (mcf6042).

One mother (mcm8079) highlighted the lack of opportunity to engage, for those who were in isolation rooms. She described a different arrangement at the specialist hospital where her son had shared care:

"I think it is one of the hardest things for the oncology children is the isolation especially when they have an admission, they are not allowed out of the room and a minimum stay would be 48 hours."

The sociability of even the very youngest children was evident. Some parents thought that the babies benefited from all the attention they received in hospital Mcf14.52004 said:

"I think for a baby of her age, she obviously doesn't really understand what's going on, but she loves having attention where people are talking and playing with her."

Despite the strange circumstances of hospitalization, the importance of human relationships was constant.

7.6.8.1 Ennui

Despite a Playroom and televisions, ennui was a problem for children who had to have prolonged stays in hospital. For children who were in for longer spells, this type of
entertainment was insufficient. This fourteen year old described how his boredom stemmed from not being able to participate in life and relationships outside hospital:

"We were in here two weeks ago just having TPN, not allowed to go out anywhere, missing your family and that's what gets you, family, close relatives, friends, you don't get enough communication, you don't get to see them enough" (cm14010).

Friends rarely came to the ward, although children received letters and cards from school. For those who were in for prolonged periods it was more difficult to sustain relationships with those outside of hospital. Cm14010 did have a sixteen-year-old visitor who came from a different adult ward to see him. I had a sense of the lives of those in hospital passing them by or with life in school and for their friends carrying on without them. Holloway et al (1998) discusses the altered meaning of time for patients in hospital. She, and her colleagues, describe time spent in hospital to "lost to patients’ everyday lives" (Holloway, et al. 1998, p.461).

7.6.9 Future oriented

Children are often considered with their future in mind as demonstrated in the Literature Review (James & Prout, 1998; 2.3.2). Examples of this perspective can be drawn from the fieldwork, for example a child was treated for a congenital dislocated hip (cf15.12028). Although at fifteen months, interference with activities was minimal, in adulthood, those with untreated congenital hip dislocations were likely to suffer from a limp and pain often associated with arthritis later in life. Dislocated hips were screened for at birth, six weeks and more often as necessary. Surgical treatment was best performed at approximately fifteen months. The process was long and drawn out and is undertaken at an age when the child is asserting independence through moving, if not walking. Treatment consisted of eight days traction and then an open reduction where the hip is repositioned, followed by a plaster cast with a hip spica where one leg is held away from the other by a splint (spica). The child’s present was sublimated temporarily with the future in mind. This denies the value and complexity of a child’s life and their relationships, their activities and opportunities that could pass them by when in hospital. Below is an extract from my observation record:
19.05.05 In the Adolescent Unit is cf15.12028 in hip traction. Her legs are bound and held apart and strung up on to a halo shaped traction bar. She had her two grandmas with her and she is twisting and turning and flipping her body like a fish on a line...As she flips around she is eating chips and later eats a sausage which she carefully peels. I get a feeling of the parents holding the anxiety while the child just gets on with life.

Children underwent tests and procedures with their futures in the minds of the medical staff and their parents. The children, I argue, were required to tolerate pain and temporary restriction of their lives because of the promise of a better future. This I argue is in contrast to the treatment options of older people who are obliged to tolerate less in the way of invasive procedures, as a reflection of their perceived lesser future. This perspective on children, and older people, is important when considering the notion of dignity. In older people the described notion of dignity is contingent upon their social position and worth (2.2.5.1). This is a more tangible construction than a notion of dignity based upon the future potential of a child.

The world of the child in the present was seen and constructed as of lesser importance in terms of the experience of gender, as social beings, acknowledgement of their lives and relationships outside hospital. There was a sense of being able to predict and prepare for their futures as being of greater importance.

*Part II: The meaning of dignity for the children and their parents*

*7.7 What does dignity mean?*

In the second half of this chapter I explore what the children and their parents understood by “dignity” and how they thought it was relevant to children in hospital. As in chapter six, I have discussed associated constructs of dignity, but this time from the perspectives of the children and their parents.

*7.7.1 Definitions of dignity*

During their interviews all the respondents were asked what they understood by the term dignity. The parents often commented that they found the question difficult and yet seemed keen to engage in the debate. Sometimes the children and their parents’ understanding of dignity emerged and evolved during the course of the interview. Often
children and parents recounted events that served to contextualise their understanding of dignity. Some of these meanings are reflected in other sections of the analysis.

Broadly speaking, responses included those that emphasized an intrinsic, inherent concept of dignity and those that emphasized dignity as an external or physical construct, extrinsic dignity. Frequently, both intrinsic and extrinsic meanings of dignity were offered by the same respondent, and I had to tease out common threads of understanding.

### 7.7.2 Intrinsic dignity

Intrinsic definitions of dignity included those that acknowledged the value and worth of their individual child and included very young children and babies. I have used the term "intrinsic" dignity as an unconditional inherent value of the child as a human being. Parents emphasized that a child was worthy, by citing respect as a notion they associated with the concept of dignity. Mcf4.12007 was a first time mother of twins who felt strongly that her four-month-old girls had dignity. I asked her what dignity meant to her:

> "Respecting them as people, as individual, respecting their space, their privacy, their rights."

A similar response was given by the mother of an eight-year-old boy:

> "Respect really, give respect for the circumstances that anyone might find themselves in, personal space, lots of different things, but respect, respect for people’s feelings" (mcm8079).

The essential humanness of children was emphasized, in this example, by the mother of an eleven-month-old boy, particularly in the first part of her response:

> "To be respected as a human being, to respect someone’s personal space. I suppose in a hospital it is a learned response, but certainly being exposed I suppose calls into question dignity" (mcm11.12064).
The quote from mcm11.12064 above suggests that she understands dignity as something inherent to being human. She also implies that dignity in hospital is quite specific and to do with learning to manage exposure.

In using the term respect, these respondents made clear what other aspects of dignity they felt were important to their child such their feelings, as a human being, an individual, their rights and their privacy and personal space. Three respondents made direct links with respect:

"Treating the child as an equal...respecting their confidentiality" (mcm6048).

Mcf15.12032 said: “Respect for an individual, maintaining somebody's privacy.”

In a similar way, Mcm17.12035 responded in her explanation of what dignity meant with:

"Respect, being in the hospital environment, privacy, Individual rather than being all the same...being explained what's going on rather than just being processed."

The choice of the term 'processed', by this mother, suggests her reaction against measures of throughput and outcome. She emphasizes her appreciation of being treated as an individual with sensitivity and good communication.

7.7.2.1 Acknowledgment

Parents, particularly those who had children with chronic health needs, spoke about acknowledging their child as a person being human (7.13). Parents saw this acknowledgment as lying at the core of respecting the child and dignity. For example this mother of a five-year-old boy in for investigations said:

"Not being made to do things you don’t want to do and reasons not being explained...treating you like a nobody...having your rights taken on board and if you say “No” then someone would take that" (Mcm5016).

The mother of a twelve year old girl with a life limiting condition and special needs, aligned acknowledgment with simple courtesy:
“Just affording the child, no matter what age, or teenager, the courtesy that one should give to an adult, but which they don’t. That would be a great thing” (mcf12080).

This mother was upset when staff directed their attention to her rather than her child. Some of the nurses on the ward knew cf12080 and her family very well, but they were not always on duty or busy elsewhere. Where other staff had to take over they tended to use the mother as a 'short cut' to understanding her daughter and in doing so, appeared to ignore her altogether.

7.7.2.2 Autonomy

Associated with the essential requirement for acknowledgement, was the need for recognition of individual need and autonomy. Autonomy for children, especially for those in hospital, may be difficult to achieve and yet is associated directly in the literature with dignity (Macklin, 2003; 2.2). Autonomy and self-determination was described and understood to be part of dignity even when considering very young children. Below the mother of a twenty-one-month-old girl said:

“Things like being able to sleep when they want to sleep, to eat when they want to eat” (mcf21.1209).

Allowing for this level of self-determination seemed to demonstrate what a very basic and fundamental understanding of what respect for a baby and their dignity might be. In a similar way, mcm6024 said:

“Dignity it’s about your freedom to be how you feel...to live in a way you feel is acceptable, to appear in a way you feel is acceptable.”

Paradoxically autonomy for older children seemed more difficult to achieve in hospital. Older children had more to lose in the sense of independence and choice, situating teenagers next to toddlers in bays restricted their opportunities to make friends and stay up late (cm14010).

7.7.2.3 Participation
Part of respecting the child, as an individual, was to engage and involve them in what was going on. Dignity was associated with a child being able to be a participant, on an equal position of power, rather than a recipient, or a body to be “done to.” The mother of a six-year-old girl who had been admitted with pneumonia said:

“Involving them in the process, rather than just being a body and not negotiating with them, taking note of what they are saying” (Mcf6042).

Another mother of a six-year-old boy who had come in for neurological investigations said:

“For me it would be treating them like they are important and that they are part of the process” (mcm6048).

Parents of young children also expressed the need for involving the children in their care. The mother of cm4052 commented on the meaning of dignity for her son when he started treatment aged just two:

“A feeling of self worth, part of the whole game plan: not just being done to” (mcm4052).

Another mother of a two year-old stated:

“The way they do things to you, not nastily, tell you what’s going on and things, not just get on and do it when you don’t know what they are talking about” (mcm2018).

Parents appreciated their children being involved in their own treatment, children too liked to participate and assume some control over their care. For example cm11046 described to me how he liked to have his bloods taken:

“Step 1, put the cold spray on your hand, step 2, pin in your arm, tape... gone, it’s easy, takes about 10 seconds with cold spray.”

Children also enjoyed playing an active role in our interviews such as asking to be interviewed (cm12066) and holding and positioning the microphone (cf6042).

7.7.3 Normality
Children were made vulnerable due to their strange surroundings (7.3). Achieving normality was directly related to maintaining dignity. One parent whose six-year-old son had Asperger’s syndrome said that promoting dignity was about:

“Trying to maintain a person’s sense of normality” (mc6024).

A sense of normality was understood, by her, to be vital in maintaining a sense of self at a time of stress. It was as if subjecting him to the strange environment of the hospital was not recognizing his individuality and particular needs and therefore his feeling of safety and dignity. To “feel safe” was a quality parents recognized as important for their children. When asked what she thought was really important for the dignity of children in hospital one mother replied:

“To feel safe I think, to feel safe and you know secure that they’re, that nothing bad is going to happen” (mcm5.12013).

A sense of safety was linked directly to dignity for children. When asked about the meaning of dignity, parents talked about how children could be helped to feel safe. A mother of a six-week old boy said this depended upon:

“How they are treated and how they are protected in being examined” (mcm6.52005).

The notion of safety is central to Hochschild’s (1983, p.7) definition of emotional labour. Talking about the work of flight attendants, she states:

“This labor requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others — in this case, the sense of being cared for in a convivial and safe place.”

Children and their families appeared to crave normality and associated with normality was safety. It is interesting to note that the children were thought by the mothers unable to experience a sense of dignity unless they felt safe. In addition, that this sense of safety could be induced directly by the behaviours and emotional labour of others.

7.7.4 Treating “as if”
The parents and children debated whether babies had or needed dignity, although all the mothers who had babies, that is under two at the time of interview, said that they thought babies had dignity. In contrast the mother of a five year old said:

"I don't think babies need dignity do they?" (Mcm5016).

Mcm6024 thought that the dignity of the child could sometimes get muddled with how the parents or adult perception of what was important:

"You know nice clothes and so forth, rather than just leaving them undressed under a sheet or something would be nice, but I am not sure if that's to do with the adult's perception of how the child should be...the dignity that the child should have,...or for the child's benefit, I don't know."

Here again the mother described a tension between the social norms of dignity, extrinsic dignity and an understanding of dignity as something less tangible but intrinsic. These discussions also raised questions, not only about whether babies have their own dignity, but whether they need dignity.

The majority of parents thought that their child had dignity even when very young. They acknowledged that children may well be unaware of dignity, although some felt that they understood it at least at a rudimentary level. In terms of the way they would like their child to be treated, they expected an "as if" approach to their care and treatment. By "as if" I mean they expected their child to be treated as if they had an awareness of dignity and in a way that any other adult should be treated. For example, mcf2020 said:

"I think at some point your child is going to become aware of what's going on at some point and unfortunately nobody really knows when that point is, so they ought to assume they do, all the time, whatever age."

Parents reflected that if they were uncertain about the child's understanding of dignity the child should be treated with the dignity of any other:

"Not knowing what their perception is, I would want them to be treated with dignity" (mcf4.12007).
Similarly the carer of a child with special needs (cf8067) said:

“You don’t know what is going on in her mind, so it’s just as important to give her that privacy as you would any other child.”

Parents wanted their child treated ‘as if’ they had knowledge of dignity, even if the child was not aware of the social norms of extrinsic dignity. For the parents it was important to see that their child was treated in such a way as to honour their dignity and value them.

7.7.5 Children’s definitions

Some of the older children were able to offer their understanding of dignity. They understood what it felt like to not have dignity:

"It means kind of your pride or something, so if somebody takes away your dignity, it means they make you look stupid or something" (cm14039).

Most commonly children associated dignity with the feeling of embarrassment, as expressed by the following comments from a twelve-year-old boy and fourteen-year-old girl:

“Your pride and what you do, whether you feel embarrassed” (cm12066).

“Embarrassment” (cf14065).

Embarrassment is an emotion associated with the transgression of socially accepted rules of behaviour. It is a response to the perception of being negatively evaluated or giving the wrong impression (Warren, et al, 2000). The understanding and feeling of dignity for the children was related directly to the impact of others; the witnesses, as well as a sense of not being seen for who they really were.

7.7.6 Theories of dignity

Parents seemed to think that dignity was constant. I interpreted this as an understanding of dignity as something changing and inherent in their child, intrinsic dignity. They also thought that a growing awareness of themselves and the expectations of others meant
that the child’s experience of dignity changed as they grew up. Thus they differentiated
between an intrinsic concept and the idea of dignity as a dynamic and socially
determined construct. Parents with younger children said that their children were not
concerned about bodily exposure, that seemed to be central to an understanding of
extrinsic dignity:

“Children aren’t so fussed about people watching them or being examined”
(mcm5016).

The mother of a six year-old-boy (mcm6048) compared the experience of a child to that
of an adult, emphasizing an adult’s need for privacy and control:

“If you are an adult in hospital for instance and you wanted to maintain your
dignity and you might not want to be in a mixed ward, or you might not, you
just don’t want to be helped to do things and feel in control, but as a child
you are not always so aware of those issues.”

Parents commented that children became more concerned about exposure and bodily
issues as they got older. When asked whether she thought dignity changes, the mother
of a five-month-old boy, in hospital, and an eight year-old daughter, said:

“I don’t suppose it does really, but I suppose as they become more aware of
their body and how, you know how they become embarrassed”
(mcm5.12013).

The feeling of embarrassment was understood, children and parents, as an indicator for
a challenge to dignity.

7.7.7 Embarrassment

The children equated embarrassment with a loss of dignity, and embarrassment seemed
to be part of their experience of being in hospital. Cm12066 equated having to wear an
operating gown, “a dress,” with feeling embarrassed.

One mother thought that children did not have the resources of an adult to cope with
embarrassment (mcm5.12013). There seemed to be a dilemma for parents about how to
react to a potentially embarrassing situation when their child was exposed but
unconcerned, almost as if they should be embarrassed for them. The mother of a fifteen
month-old girl (mcf15.12028) undergoing traction described the scene when she had to
change her daughter’s nappies in the presence of others who were potential witnesses:

"Bottoms up in the air, she is very innocent as well so she doesn't see that
there's a problem and I never see that there's a problem but..."

Alternatively, parents could negate views expressed by younger children, this could be in
an attempt to be a 'good' parent. Below is an extract from my observation notes:

I meet cm5084 who is five and a half and has just come back from 15
minutes in theatre following a tooth extraction. He is crying and distressed.
His mum says "He doesn't like his dress (the theatre gown) he thinks he
looks silly!" (looking upwards). "You have to wear it" she says to her son. I
feel she wants to be compliant and good at the expense of her son's wishes
(7.12.05).

On reflection this seems like a harsh judgment of the mother, but the child was back
from theatre. I argue that mother was inhibited from helping her child change, or seeking
help by her need to be uncomplaining and 'good' in the eyes of the staff.

A mother of a six year-old girl said she thought "dignity matters the same", but thought:

"Where they are younger, they have less inhibitions and as they get older,
they become more aware of similarities and differences and things like that"
(mcf6042).

The children spoke about increased feelings of embarrassment as they got older.
Cm14010 said about his earlier admissions:

C:  "I was a lot younger, so it was a lot easier."
R:  "It was easier?"
C:  "You know like not, not embarrassing."

Similarly, cm14039, a fourteen year old boy in answer to whether dignity changes as you
grow up said:

"I think you become more aware of it as you grow up, 'cos when you are
little you get embarrassed less easily."
Cf14064 associated embarrassment with loss of dignity and when asked if she thought dignity changed as you grow up said:

"You are much more aware of your dignity in your teenage years being in hospital. When you are about five, then again when you are older, the dignity issues are a lot less."

The older children, adolescents, became more aware of how they present themselves in terms of dress and behaviour and how this could and was interpreted by others, including their peers. Embarrassment was interpreted by parents to be an indicator of a growing sense of self awareness and personal dignity.

7.7.8 Presentation of self

Children expressed concern about how they wanted to present themselves. For example, twelve-year-old cm12066 explained that he worried about what he would wear during his hospital stay for a minor orthopaedic procedure:

M: "You didn't want to be naked did you?"
C: "No."
R: "You wanted to make sure you were covered up and actually that (the gown) is right down to your ankles!"
C: "Yes, it makes me feel very secure" (laughing).

In my interview with cm14039 we spoke about a range of events that made him feel uncomfortable or embarrassed, he replied:

C: "Having to wear a gown made me feel a bit stupid, but apart from that I've been... It was just a bit, silly little thing, it was just embarrassing having to wear it."
R: "Right did they take you down to theatre in it?"
C: Yes, they did in the bed, which I thought was a bit strange, because I could have just walked."

Not all the children were concerned about how they might appear to others. One such child was (cm14066) who has Downs Syndrome. His mother commented on how her older daughter would have been embarrassed being taken through the corridors and past the café on the way back from theatre. She spoke of her son "He doesn't mind, he
was sitting up, smiling and waving with a mouthful of blood." (Observation note 21.07.05).

Adolescence is a period of transition and individuation where the child struggles to separate from the parent. It is a time characterized by physical changes and a particular sensitivity about their body and a desire for control over their bodies. To be seen to have this control is paramount. Hence the notion 'to be cool', meaning to be in control, to be calm, unflustered, and not able to become embarrassed. Adolescents become more aware of their sexuality, and also their potential sexual meaning to others. Older children are no longer comfortable about being seen naked by others.

Mcm8079 identified the need for staff to recognize the changes in an individual as they grew up. For the children who return over a period of years this is particularly important:

"In the period from when he was diagnosed, at five, and now he is nearly nine, he has obviously matured a lot and doesn't like to be patronized, he doesn't like to be spoken to like a little boy."

I wondered if, at this point she was also talking about herself, and her need to be acknowledged as an expert in her own right, following four years of enduring her son's treatment.

7.7.9 Learning dignity

Parents described the children as "vulnerable" (7.9.6). The father of a fifteen month old girl (fcf15.12032) thought that this was particularly so for younger children who did not have a developed sense of their own dignity. This, in itself, made them vulnerable. He continued to describe a model of learning about dignity from the parents. The child's mother (mcf15.12032) thought that the behaviours of their children, particularly around bodily exposure were influenced by the way they, as parents, modeled behaviours:

"What is an acceptable way for them to be treated by other adults and children and what is not and if they are not getting those lessons at home then that may make it difficult in situations outside the home, where boundaries where we feel are inappropriate may be crossed..." (mcf15.12032).
Similarly, a mother of a six-year-old girl said:

"Children look to you to see what is acceptable and if you give them the 'yes, you can do that' then they will be happy doing it, so I suppose really providing a positive role model" (mcf6042).

The appropriate ways for children, and for adults to behave in relation to children, was thought to be modeled by parents and when they were absent, by nursing staff. Fcf15.12032 reflected on how children could learn the social norms of dignity in hospital and thought this:

"..put a greater onus on the nursing staff... to define what is and isn't acceptable 'cos there is less scope for an interaction for a child to say 'well I am not comfortable doing this or I don't want to do that, or I want to step behind this curtain please.'"

This has considerable implications for staff looking after children who are in hospital for a long period of time or who have frequent visits to hospital. Some children may find learning the way to behave in a socially acceptable way more difficult and this could include the way dignity is understood. Mcm6024 spoke about how her son's Asperger's affected him and how he needed additional support at school:

"He needs somebody there to make sure that he behaves in a way that he's supposed to behave at school, because he doesn't automatically know how to behave."

Similarly in hospital, he did not always behave in a way that others expected him to do. There was a hesitancy of staff to go in to him. I was told, by staff, that his parents did not want too many visitors, but I found this not to be the case.

7.8 The Body

Adults assume control over much of a child's life and this extends to control of the child's body. This was most apparent in hospital where the bodies of children became objects of interest, discussion and examination. Their appearance became the source of conjecture as to their underlying condition, not just to the staff, but also for visitors to the hospital, in the café or in the lift and to me as researcher not least because their
diagnosis was not made known to me. The children and their bodies became defined by clinical gaze and medical measurements. Foucault (1973) documents the transformations in medical practice that took place towards the end of the eighteenth century. He describes the way the body became the new ‘anatomical atlas’ to be interpreted through the ‘clinical gaze’. The role of the patient diminished as the body became the object of study (Williams and Bendelow, 1998).

7.8.1 Power over bodies

Children are accustomed to adults having power over them. Their position in relation to adults was picked up by mcm6024 when she was talking about whether dignity changes as you grow up:

“So your perception of how you should be treated changes quite a lot and children do expect a certain amount of manhandling” (mcm6024).

She uses the term manhandling here to convey a way of dealing with children, and their bodies, in a physically controlling and dominating way. This can apply particularly to those children who have long or frequent hospitalizations. There needs to be an appreciation of the child's developing awareness of their bodies and exposure. Power needs to be carefully negotiated as the child grows up into adolescence. Children who have many or long periods of time in hospital can experience a considerable amount of handling by strangers, but all children are subject to bodily investigations and surveillance. As Alderson (1994, p. 46) states:

“Children are also the group most subject to routine invasive investigations, and interventions such as immunization, through child health surveillance.”

Sometimes it seemed as if the child was at the mercy of the vagaries of his, or her body. For oncology children who became pyrexial in the night, it meant a late night drive to hospital in case it should mean the start of an overwhelming infection (cm4052). The importance of the child within the body, the embodied child was recognized to be vital by mcf6042:

“Involve them in the process rather than being a body and not negotiating with them.”

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Thus she emphasised the need for her child to be involved in care by the health professionals. Children need to establish an embodied identity of themselves as they grow up that needs to be respected by adults around them. Some children spend a considerable time in hospitals, being manhandled or examined. The challenge to establish their own embodied identity is great and this needs to be acknowledged by staff. They need the help and sensitivity of professionals to assist them with this process.

7.8.2 Boundaries

The term boundary here applies to the actual and metaphorical skin that separates one from another and contains the individual. Children became more aware of their body boundaries as they matured. Parents were aware of how children could feel self conscious about their bodies, described by one mother as “a body shy thing” (mcm6.12005). They recognized that older children were particularly self-conscious about their bodies, but thought that younger children were less so.

“Young children don’t really have any inhibitions, so although you should give them privacy they are not so worried about it, but as they grow up, then they are going to be more concerned about it” (ccf8067).

“I mean I think children this age do not mind running around naked, whereas older children and adults would be bothered by something like that” (mcm4052).

One mother (mcm14066) commented on the operating gowns being open down the back with the child expected to wear no pants underneath. Older children were able to express for themselves anxiety about exposing their bodies and being able to go to the toilet and wash. When asked what she had been worried about before she came in cf14065 said:

“…not being able to do stuff for myself, but they have made it fine – like going to the toilet, or having a bath or something like that.”

Some of the older children expressed concern over losing bodily control, including becoming unconscious for an operation. For example (cm12066) spoke about his fears of being frozen in his body, unable to move, but being able to feel everything. He also
talked about how he had been unable to "pee into a paper urinal" as if his body had betrayed him. As he had persevered, his mother had asked him what he had to lose, to which he answered, knowing the focus of my research, "Only my pride and my dignity." Alderson (1994) argues in her account of children's rights to integrity that the lesser sense of self young children are assumed to have, renders them more likely to have their bodily boundaries and integrity, violated.

7.8.2.1 Cannulae

The children were affected by the taking of blood and by cannulation. This was when a cannula was inserted and left in situ to facilitate the giving of drugs and fluids intravenously. Where possible local anaesthetic cream such as Emla® cream or cold spray was used to alleviate the pain of cannulation. Emla® cream needed to be put on and covered with an occlusive film dressing approximately 45 minutes before cannulation. Even in cases where analgesia had been used, the child did not always benefit:

“They put the numbing stuff on my hand, on like both of my hands, then like they, the doctor went and took blood out of my arm, 'cos they couldn't find a vein on my hand. It was on my hand for ages and then they went and took it without the numbing stuff" (cf12006).

Cf12030 had been readmitted to hospital following a post tonsillectomy infection. She spoke about having a cannula put in:

R:    "Did that hurt when it went in?"
C:  "Yes, but it didn't hurt as much as I thought it would."
R:    "Did they put the cream on beforehand?"
C:  "No, because they had to do it quicker, and they couldn't put the cream on because it takes an hour for it to work...They couldn't find a vein."
M:  "There was blood everywhere wasn't there?"
C:  "Yes."
M:  "Frightened her a bit."

Cannulation corresponded with legitimizing the illness of the child. So in Ambulatory Care, for example, a cannula was inserted when it is decided that the child would be admitted. Despite causing distress to children, cannulae seemed to be left in place until
discharge was imminent on the basis that venous access may be required in an emergency post operatively, or at some time during admission. Cannulation limited the mobility of the child as one mother of a child with chronic illness described it:

"Unfortunately they are going to lose their independence as soon as they get a venflon (cannula) put in" (mcm14010).

Cannulation was the source of pain and anxiety for children. C14010 had been in hospital for fourteen weeks. He had kept a record of the number of missed cannulations he had endured: “Sixty five”.

For children who needed intravenous drugs over a long period of time a ‘portocath’ was positioned under the skin of the chest. It was also used to take bloods. Cm4052 called this his “Wiggly” and it became an extension of his body:

C: "I liked Wiggly."
M: "You remember Wiggly?
C: "I liked Wiggly now he’s lost...A very long time ago we started looking for Wiggly but we couldn’t find him anywhere, couldn’t we Mum?"

Children who have portocaths and catheters were encouraged to take care of them themselves as if they were a part of them and to encourage independence. Cm4052 went on to describe how he used to play with Wiggly when he pretended to be the doctor.

7.8.3 Connectedness of parent to child.

The bodies of parent and child were almost connected. By this I mean that they frequently touched, or sat very close to one another, or even shared the bed. The parent usually went down to theatre with the child and accompanied them back:

*Another child comes back from theatre. Mum is on the trolley and the little girl is on her lap looking quite happy* (4.05.05).

Throughout the interviews parents, when asked about their child and their hospitalization, responded in the plural as “we” and “us” rather than he or she.
Sometimes they even referred to themselves as the patient. It was as if they were one, as if the experience was shared inextricably. This sense of connectedness was present when the parents described working to control their emotions lest they should rub off on their child. On occasion parents spoke of the feelings or behaviours of the child in a way that may have been a reflection on themselves and their own emotional state:

*Cm5081 is being seen by the doctors in Ambulatory Care. According to his mother, "he is not a good patient". I wonder if this is helpful and feel that she is talking about herself, at one level, as she is obviously finding it difficult (9.11.05).*

I wondered how much the parent took on the meaning of a diagnosis and the anxiety and concern for the future on behalf of the child when they were seemingly oblivious to a diagnosis:

*It's lunch time and the father of cm20.12001 is looking tired and stressed. He is walking up and down the corridor following his little son as he fiddles with door handles and fire extinguishers on the wall. He is now waiting for an MRI scan. They have not found any lumps around the brain that the doctor suspected...but he is having up to forty fits a day...Dad is watching carefully as cm20.12001 could stumble easily and hurt himself. His Dad has been there all night and they are waiting for Mum. Here I sense the weight not only of what the diagnosis might be, but also something of the bearing, on behalf of the unaware child, the enormity of what he and his family may have to face (15.04.05).*

By maintaining the dignity of the child, whether the child was aware him or herself, the sense of dignity of the parent was maintained. This was acknowledged by one of the respondents (mcf6042) when she spoke about the hospitalisation of an infant:

*"I don't see any reason why you can't still do the curtains for privacy. It probably helps the parents as well. By pulling the curtains the sense of exposure is reduced."

The intense engagement of parent and child was made more apparent when someone else was accompanying the child. I noted that nannies (n=3), when present with their child charges on the ward, were visibly less connected with their charge. In the following example, also less able to speak up in defence of the child:
A doctor asks if he can take blood from cf1045 whilst I am talking to the
nanny. He seems unsure which of us to ask and does not introduce himself.
Dad is around but the nanny is with the child at the moment. The doctor
takes the child to the treatment room for blood to be taken. Later I see the
Dad is looking for his baby, he can hear her cries from the treatment room,
but cannot find her" (7.06.05).

On my visit to Accident and Emergency (22.4.05) I noted the behaviour of the adult
accompanying a school boy different from what I would have expected of a parent. I
noted in my observation record:

I wonder why the woman with the boy, who he seems to quite like, looks
vaguely embarrassed and stands at the foot of the bed rather than with him
(22.4.05).

I later discovered her ambiguous behaviour was a reflection of her being the school
nurse rather than the mother.

7.8.3.1 Physical connectedness

Mcm2021 described her feeling of connection with her two-year-old son as she
explained her view that dignity is the same for a young child as it is for an adult:

"I've thought that because it, it's kind of channeled through you, so its very
connected, if you have a young child anything that happens to them, it's
happening to you."

The physical nature of the bond between mother and child was noticeable from a
number of comments:

"I think the most important thing is being able to have their parent of carer
there and if they are little, for them to be able to actually sleep next to them"
(mcm5016).

One mother (mc5.12013) described how she had been asked whether she had wanted
to stay for the lumbar puncture to be performed on her son. When the nurse said she did
not have to, she left, but she felt the need to wait just outside the door to be as near as
possible. Mcf12006 spoke of her distress some years before with her six-month-old son,
when she had to sleep down the corridor from him:
"I had to be here all the time and found that actually quite distressing to be apart".

She compared that experience to the present day:

"Mums be there all the time as far as possible, right down to when they go down and have their operation. You just have that little separation and then you're there as soon as they come out, you're there by their bed. I think it helps them recover, just gives them security, knowing that there's someone there, loves them, with them" (mcf12006).

Mcm2021 recounted the time when her baby son did not come round from his operation, at a different hospital. She described a mutual, physical bond or need between them:

"I knew that he... he just needed to breastfeed and I had to wait 35 minutes while they plugged him into a thousand machines and then finally, when they actually let me get to him, he was so relieved and he had a feed and he was better."

Throughout the interviews parents, when asked about their child and the experience of being in hospital, they would respond in the plural as "we" and "us" rather than "he" or "she". It was as if they were one, as if the experience was shared viscerally. This sense of connectedness was present when the parents described working to control their emotions lest they should rub off on their child. This sense of emotional and physical connectedness makes the necessary and expected relinquishing of their child and the trust given to the medical team more poignant.

7.8.4 Legitimisation of illness

Before a child was treated, or admitted, there needed to be a formal confirmation that the child is truly unwell. This was done through a variety of tests and measures and the identification of symptoms during history taking, in a process that I have termed legitimization of illness (6.8.5). The trajectory of the sick child through the hospital commenced at this point. The process of legitimizing illness is, in part, dependent upon the parent relinquishing control of their child to one acknowledged to have expert knowledge. Allan (2007) describes the concept of liminality as described by van Gennep (1909/1960, cited in Allan, 2007) to describe a transition between one social status and
another. "Liminality" creates time and space for this rite of passage to take place. Thus
the child separates from the parent, and enters into the transition stage where his or her
illness is legitimized, before being acknowledged as "ill" by the health professional and
incorporated into the institution of the hospital. The period of investigation and
surveillance that characterizes the legitimization period is a time of uncertainty and
anguish and can be prolonged in the attempt to establish a diagnosis.

In the Accident and Emergency department, the parent had to make a case for why they
thought their child was ill enough for them to be brought to hospital. The doctors then
had to legitimate the illness. They did this through vital signs, the interpretation of pain
and X-ray. Mcf6042 described her difficulty in getting her daughter admitted. She had
been urged to seek a diagnosis of her daughter's illness from friends who were in the
medical profession:

"These friends were sort of saying 'she needs to see a paediatrician' they
said 'and push!'"

She was grateful for the input of these friends who understood the system and
recognized that she might have to be assertive to make her worries about her child
heard.

"They thought maybe it was meningitis or something like that and he said it
might be worth saying the word and seeing what happens."

Her daughter was diagnosed subsequently with pneumonia and admitted. Her mother
expressed her self-doubt prior to her child's illness being legitimized:

"I was beginning to think, oh maybe, you know maybe fuss...so I felt
justified, for fighting my corner."

Increasingly parents and children have access to information, from the internet for
example, that can help them understand what could be wrong with their bodies when
they are feeling unwell. It should enable them to seek and obtain appropriate treatment
as necessary. However despite this demystifying of bodies through information, it could
sometimes be difficult to access the gatekeepers to medical assistance. Another mother
recalled the events that led up to the admission of her daughter with severe abdominal pain:

“She was saying the pain was in a particular place, so he (husband) looked it up and thought it was appendix. So when I got home, he rang the doctor and they wouldn’t come out” (mcf11087).

In this case the parents had to ring again and were told to come to the hospital where their daughter was found to have acute appendicitis.

Mcm6024 also told her story of getting her son’s illness acknowledged and taken seriously:

“He broke out in a spotty rash on Friday. We took him to the GP. She said she thought it was just a virus and she gave him some antihistamine to take for it, but he had a raging temperature on Friday night...By Sunday morning he was screaming in pain from his back. By which point we ‘phoned .....They were very unhelpful. They took an hour to call back, in spite of the fact that X was in pain and I was wondering whether I needed to call an ambulance.”

Eventually she had to carry him into the “Out of Hours” surgery where she recalled:

“We waited in line in a sort of queue to be seen.”

In the same way that criteria must be met to establish illness worthy of admission, so measurable objective criteria must be met to legitimate “wellness.” For example, after surgery proscribed measures legitimate wellness and time for discharge. These signs included drinking, eating and satisfactory vital signs such as temperature, pulse and respirations within normal limits. These factors seemed to take precedence over the subjective experience of the child and translation by the mother.

Mcm9056 walks past me on the way to the car park. Cm9056 walks past very slowly, he looks very pale. “They let them out so quick don’t they?” says his mum recognizing me. To demonstrate my understanding, I ask her “Is he still feeling poorly?” and Mum nods (13.07.05).

Objective measures of the child’s body legitimized ‘illness’ and ‘wellness’. This legitimation had the effect of managing the uncertainty and anxiety over the child’s well-being, sometimes by casting the embodied experience of the child into shadow.
7.8.5 Pain

In the Accident and Emergency department, children were given pain relief such as paracetamol by the doctor at a dosage based upon their body weight rather than on the level of pain they reported. This was in spite of a ‘pain ladder’ used, as a tool, by the nurse to assess the level of pain the child was experiencing.

The amount of pain a child was likely to be experiencing was anticipated on the basis of other children having similar events. Children who said that they were experiencing rather more pain than predicted were sometimes subtly derided by staff. For example a nurse was imitating the bent over stance of cm10023 in the corridor. The other children could also react in this way. Cm14010 had been in hospital for eleven weeks and sat opposite cm10023. He had made friends with another child and together they were looking on and, to me, it seemed as though they were smirking at the discomfort cm10023 was having from his operation site and his cannula. I wondered whether some of these behaviours were in part a response to the aggression cm10023 displayed when he first came in. Cm10023 had been quite rude in answering questions posed by the doctor clerking him in:

“I don’t want to be here, nobody wants to be here!”

And later: “I would rather be at school!” When I asked him two days later, after his operation, about this. He said they had had to wait around and be seen by various people asking the same questions. Cm10023 said that this was “not convenient” when he was in pain. I remembered his mother’s reaction when a junior doctor asked her if he had been a normal pregnancy to which she asked: “Is this relevant?” It was as if she had picked up on the frustration and pain of her son. A mother of a child who had had many hospital admissions offered this insight into aggression:

“Most people in hospital can become aggressive, because they are actually frightened, parents and children” (mcf12080).

I observed how children were assessed in the Accident and Emergency department (22.4.05). If pain was described as rather less than predicted (A&E) then the doctor was likely to doubt a diagnosis. An eleven-year-old boy came in following a cricket accident.
The doctor asked about his pain on a scale of one to ten. When the boy scored it as "six" the doctor did not seem to think this is very high for a fracture. After his X ray, confirming a fracture, the father explained that his son has had "terrible pain with a grommet in the past" as if this had increased his tolerance of pain.

Similarly, in Ambulatory Care (26.05.05) a doctor asked cm9041 to score his pain on a scale of 0-10, to which the boy replied "8". He was pale and tired looking. The doctor responded with:

"That's pretty bad for a smiley kid -- don't usually smile when you are eight out of ten, can I take a look at you".

I wondered whether this was reassuring patter from the doctor, or whether he did not believe that the pain was as severe as the child said it was.

Children may have vastly different perceptions of pain as in the case of cm6024 who had Asperger's syndrome a condition characterized by unusual sensory perception. His mother explained:

"It's quite difficult because, um I've heard of some of them that's had quite severe problems and experienced very little pain. Or you can have a minor problem and experience a lot of pain from it, more than the average person would have."

On occasion the amount of pain children experienced was made light of. Cf11087 needed an appendicectomy and was in pain going down to theatre for her operation:

R: "Did that seem like a long way?"
C: "Yes, it was quite bumpy and they only told me when the bumps were there when we had gone past a few" (As if they were not taking her pain as seriously as they might).
M: (Recounting the journey) "Oh that was a bump. They were fun weren't they?"

I sensed the relief of the mother of cf11087, now that her operation was over. I also wondered whether her daughter, the patient, was not ready to let go of her experience of pain and needed more time to acknowledge and come to terms with it.
7.8.6 Bodily Appearance

The bodily appearance of the child was important in how that child was perceived and understood by others. The child was brought to hospital to be ‘looked at’ to be put under the clinical gaze and also the gaze of the others on the ward and me as an observer. I found myself reacting to some children in response to their appearance and noted this down in my observations as an indicator as to how others may also respond to them. I have identified four types of reaction below:

- Children who looked different: these children included those children with special learning needs or complex care needs
- Children who looked like adults. The age of the children spanned from newborn to sixteen some of the children looked adult even though they were in their early teenage years.
- Children who were obviously injured or looked unwell. Some of the children looked very unwell while in hospital, either through injury such as a boy with a very swollen face and head (15.4.05) or cm9022 who was very yellow and listless. Their appearance induced a sense of shock in me, and no doubt others, on the ward.

Priestley (1998, p.208) describes a “preoccupation with pathology and impairment” as a strand of child research. He critiques the drive towards measuring the bodies of children against physical and cognitive norms. The children demonstrated they were aware of what their appearance and difference from the norm, meant. When I spoke to cf14065 about being in hospital she explained:

“I had a deformed jaw, my bottom jaw is too long and they had to put it so I have a proper bite.”

7.9 Control

Family centred care is dependent upon parental participation and a mutual understanding of roles. Fundamental to these two elements is the negotiation of control. Admission to hospital can be disempowering for many people. Children generally have little opportunity to exert control, or make choices over activities, surroundings or the way they are treated by others in daily life. The child is “positioned as the passive and
dependent object" (Christensen, 2000, p.38). The process of legitimizing illness (7.8.4) was, in part, dependent upon the parent relinquishing control of their child. In the hospital this could have the effect of making them more compliant to treatment and the wishes of the medical and nursing staff. As mcm6024 suggested:

“A child is less free to do as they wish, so in a sense they are more likely to be, to put up with medical procedures...I would guess on the whole.”

As children grow up they are able to assume more control of themselves, their bodies and their presentation of themselves to the outside world. I would argue that a fear of loss of control grows in parallel. The older children described a greater awareness of their presentation of self and appeared to resent the control others took over them. A fourteen year old spoke about wearing a gown in preparation for theatre:

“Having to wear a gown made me feel a bit stupid” (cm14039).

Some of the younger children also attempted to control their environment and those around them. The mother of a fifteen month old (mcf15.12028) commented:

M: “She is such a tinker with them, I mean she throws a hoolie (shouts and screams) when she sees one of those blue shirts coming in.
R: “What does she do when she throws a hoolie?”
M: “She screams, she just screams at them.”

Sometimes parents resented the control, and the routines of the ward, imposed upon their child:

“Its strange enough being in hospital apart from the fact that you have to stay up till 9 o’clock because that’s when they turn the lights off” (mcm5016).

Equally the older children resented their life being constrained by lights coming on early in the morning and being switched off early in the evening.

7.9.1 Choice
The children who had been to hospital on several occasions had taken control over some aspects of their care and were able to make choices over how procedures were done. Mcm11046 and his father spoke about how he preferred to have needles:

F: "He likes to have it done quickly, bang, bang over and done with.
C: "Yeah. Step One: Put the cold spray on your hand. Step Two: Pin in your arm, tape...gone, it's easy, takes about ten seconds with cold spray."

Cm11046 continued:

"Cold spray, yes that really numbs your hands quicker, the magic cream, you have to stand there for a long time, so have the spray."

Another child who had also had repeated stays preferred the cold spray to the Emla® cream (cm4052).

It was apparent that children were better able to assert themselves and their choices in the presence of their parent. Cm8079 needed a needle taken out (4.10.05). He was anxious and the junior doctor was introduced and it was requested by the senior doctor that the SHO remove the needle. Cm8079 motioned to his mother and made a comment in her ear after which she requested for the doctor he knew to remove the needle.

7.9.2 Control of parents

The parents too, in particular the ones who were resident, were controlled by the ward routines, as much as the condition of their child. One mother (mcm3018) told me of a time when she was resident with her daughter, as a baby:

"Some babies are here for a long stretch and their mum needs to go and have a bath and they need to go out and ..I remember going out to Tesco and buying myself a magazine and going 'wahoo!' it was really exciting."

Similarly another mother described the exhilaration she felt when she did leave the ward albeit for a short time, in her quest for normality:

"'Right I'm going out! (laughing)...breaking out to Tesco!' (mcf6042)."
Parents who had had to be in hospital for longer periods of time, and were 'living in' hospital were able and did take some control over events. For example I arranged a time to come back and interview cm14010 and his mother, at their request, at a time more convenient to them. In contrast, the children and parents who had shorter stays and were "visiting" were keen to be interviewed there and then at my convenience.

The control of parents in some cases was made very explicit, such as the sign stating that no hot drinks should be taken into the playroom, "staff only" signs on the beverages point and the signs by each bed that state "Fold and tidy away your z beds by 9 o'clock". This rule was not adhered to by mcf15.12032, who justified her actions by saying that it was for the good of her daughter. She stated:

"...but actually I need it (the z-bed) for her because I am not going to put her in the cot and fight her and just let her scream and cry if she just wants to be with me 'cos she is vulnerable and not very well."

Sometimes parents found relief in having all the responsibility for caring for their sick child taken from them:

"I mean that's a relief for me, because I've struggled to control his condition for a couple of days at home on my own and it was really too much to be honest" (Mc6024).

The uncertainty experienced by parents about their position and rights on the ward (7.5.4) had the affect of wrong footing parents in a way that disempowered them.

7.9.3 Control by parents

Parents spoke about their difficulties in exerting control over consultations. Mcm17.12035, who attended frequently with her son, spoke of how it used to be before the new ward opened. She used to have open access to the ward which meant she could 'phone the ward direct when her son was ill and come straight up to the ward and into one of the baby rooms. Now with the opening of Ambulatory Care she felt uncomfortable with the lack of privacy. She described a typical scene:
" 'Now what seems to be the problem?' 'Well tell me a bit about his history' and I don't want everyone on the ward, whoever they are knowing about epilepsy and cerebral palsy and everything else and I think it is absolutely disgraceful that a doctor will sit there, he may pull the curtains so that you are in a so called private bit and everybody's listening. And I just refuse now. I say 'No! shall we go somewhere private?'".

However it was not easy for her to take control of the interview with the doctor in this way, she continued:

"I immediately start to panic and just think 'Oh my God, I'm I'm going to have to end up having to say 'Can we go into a different room?' And it's not a nice position to be in at all."

Feelings such as these are recognized as recurring themes in the treatment of children with disabilities in hospital. The National Service Framework for Children and Young People (Department of Health, 2003) sets out guidance for best practice in the care of children in hospital. The document identifies the shortfall in the practice of admitting a child with a long standing health problem: “they insist on taking the child's details again; parents get fed up with having to tell the same painful story over and over again" (Department of Health, 2003, 4.5.3).

7.9.4 Using the space

The ward environment and the way it was used was important in terms of child/parent and professional dynamics (5.2.11). Some of the parents described the way doctors used space and held power in dramaturgical terms. Mcm5.12013 described how children could become frightened:

"I suppose if the doctors have gone away and huddled, all in front of the child and going oh, oh yes and big words are coming out, I suppose its going to frighten them even more."

7.9.5 Holding knowledge

Giving and withholding information and knowledge came up in my discussions with parents and children. Mcm6.52005 described her thoughts about giving children information:
"They have as much right to the information as adults do even if it is the simplest of terms, a little bit of information, just telling them something. I do sometimes think we shelter children a bit too much and not give them any information which I think sometimes can make things worse...It's as frightening not knowing as it is knowing."

This latter comment might say something of her own situation where she had been in hospital with her baby for weeks while they undertook a variety of investigations without drawing any firm conclusions.

Another mother struggled with the principle and appropriate timing of sharing information with her child of six about possible diagnoses and prognoses:

"They have wanted to talk about the problem in front of ...and I have been very keen that he is not to be made aware of the problem because up until now he has not been aware that he has a problem and so I have been very keen for them not to discuss it in front of him" (mcm6048).

The sharing of clinical knowledge with parents and children seemed important in the involvement of children and their parents in allowing them to feel part of the process. Equally, parents felt disempowered when they lacked the every day knowledge of where things were and routines of the hospital. As Corlett and Twycross (2006, p.35) found in their critical review of research regarding parental participation and role negotiation:

"An important element in the ability of parents to engage in negotiation was the familiarity parents had with the hospital environment."

This was concurred in this study. Parents were even uncertain if they could go out and felt judged if they did leave the ward:

"The parents are a bit left to their own devices and then it's a bit awkward 'cos you're not quite sure whether you've got that much flexibility to get out or whether you should be around" (mcf6042).

7.9.6 Vulnerability

Children and especially sick children are physically vulnerable and need the care and interventions of adults. This vulnerability in itself makes a child more at risk of being
exploited and their dignity needs protecting. Babies were thought to have dignity in the same way as anyone else among parents. However, they were described as being more vulnerable in various ways: they could not communicate their needs, they were not listened to, babies were physically vulnerable and totally dependent upon others for their basic needs. Parents and the older children assumed that babies did not have an awareness of the socially acceptable ways of demonstrating dignity such as covering the body and controlling emotions. In addition they were made vulnerable by their size and the way they could be picked up and physically manipulated with ease. Respect for the babies accommodated these special characteristics.

"They (babies) are helpless really to help themselves," stated mcf6042.

Parents were acutely aware when sufficient consideration was not given. Mcf14.52004 described when a doctor had removed some tape from her daughter's face leaving a red mark:

"Yes, that's where the doctor did actually pull it off quite quick and did actually start to bleed, so I think care and attention for small children because their skin is very soft."

Mcf14.52004 described another occasion when:

"The doctor was going to tape the lead to her hair and her head and the nurse sort of pointed out that wouldn't be a very good idea because that's going to be quite painful when you remove it and also it could leave a little bare patch on her head."

Particular vulnerability was not just associated with babies, but also those with special needs. Mcf12080 described how her daughter, who was immobile and unable to use speech to communicate, had to have the dressings removed from her back after a lengthy operation:

"She was lying on her side 'cos all we could do at that stage was turn her from side to side and he just went up and he got her by the back of the neck and he ripped them off...I was really angry, I was nearly in tears, the nurse was in tears."
Mother and nurse were upset and angered by the unthinking practice of the doctor illustrated by this example.

7.9.7 Passivity of child

Associated with vulnerability, was the passivity of the child in their treatment and care. Parents spoke of the experiences of their child in hospital in a way that accentuated the passivity of their child:

"So she was prodded and poked and having tests every day" (mcf21.12019).

The term prodded and poked came up numerous times during interviews. It has connotations of the integrity of physical boundaries of the body being tested uninvited. Children, including those who had had long and chronic health problems were quite passive in their role as patient:

"A lot of times they’ll come and do things to kids when, and not bat an eyelid and hoick them off and just do things without saying ‘Do you mind?’" (mcm5016).

Parents felt that children were used to taking a passive role:

"I mean babies are again more used to being controlled by adults" (mcm6024).

Parents were in favour of a more equal relationship between child and health professional:

"Being sensitive to them, listening to what they are saying, working with them, a partnership thing" (Mcf6042).

However, two of the children who had had repeated hospital admissions talked about choosing, deliberately, to take a passive role and surrender to the system, letting the staff get on with it in order that they could get better as quickly as possible. When I asked what was really important for children in hospital mc11046 answered:
"The only thing that is important is that the kids there try and get back and get out of that hospital, 'cos most kids don't like hospitals. To stay in hospital, let the nurses take care of you and get it over and done with as soon as what you want, basically."

A mother mcm8079 described her son's attitude:

"As the years have gone by, he's been pretty philosophical about it, he knows that if he gets a temperature in the middle of the night he knows what that means so, he's developed his own strategy for dealing with things really."

Cm4052 was diagnosed when he was two years old and although free from disease, he still had to attend the hospital on a regular basis. I asked him what was important for children when they are in hospital. In response he told me of how he had learned to cooperate and be compliant with his treatment:

C: "I always keep still...when I have my tummy done...and sometimes it frightens me doesn't it?
M: The noise from the X-ray."
C: "Yes."

These children had chosen to be passive and trust in their treatment as a way of minimizing any pain and anxiety.

7.9.8 Coercion

Throughout the fieldwork, power relationships and the use of power was an interesting component of dignity. Here I am using the word "coercion" for power over people (6.9.1.1). The staff were in a powerful position in relation to the child patients and their families. This power was recognized by mcm6024:

"They (the staff) are in a sort of controlling position. It's more likely that children are going to go along with things they are not comfortable with, so it's important that hospital staff, just sort of bear that in mind."

One parent (mcm5016) described the way staff could negotiate with children when they approached them for procedures:
"He was like 'No don't touch me! I don't want it done!' but at the end of the day he needs to have it done and the nurses always, normally they try and wheedle round and do things, get them able to touch things and feel that they are not going to hurt, and let Mummy have it on. Yet sometimes things have to be done quick and also nurses don't have all the time in the world to be faffing around persuading people who don't fancy the idea to do things."

Another parent, mcf15.12028, said:

"There have been moments where it hasn't been dignified for her. She doesn't like the oral medicine and that's been really tough because you have to hold her down and that's not very dignified."

She continued in an attempt to rationalize this by saying:

"She is fifteen months and she doesn't understand why we are all doing this, but I think she has played a big role in it, she's told us when she doesn't like things, but as soon as it's been done it's almost forgotten."

When asked what she thought about children and dignity, the mother of a twelve year old girl, mcf12006 said:

"If they are feeling uncomfortable, for them to be able to say they feel uncomfortable, but not even to put them in that situation."

The controlling position of staff and their ability to coerce was recognized by parents. They rationalized the coercive nature of some of their behaviours by acknowledging the need for treatment and believing that such actions were soon forgotten. However, some parents (mcf12006) clearly felt more uneasy with the susceptibility of their child to coercion.

7.9.9 “Best interests”

Doctors tended to talk more with the parents, and indeed parents demanded the attention of doctors more than the children. For example they could follow the doctor from their bay, unlike the children who were frequently restricted in their mobility. Procedures were done to the children that they did not like. This was usually sanctioned by the notion of ‘best interest’. In other words an action was taken that, it was assumed, would in some way help the child now, or in the future. It was not what the child might
want right now, but the need for the intervention was identified by a staff member (6.9.1.4). I noted in my observation record:

A doctor wants to take blood from a baby cm1090. The baby is still crying. “I always think it better to crack on and do it” says the doctor. They want to give him a nebuliser, but they need him to go to sleep. His parents are obviously very concerned for him, they have been up since 2 a.m. The child is desperate for sleep (14.12.05).

Staff and parents had a considerable power and control over the children in hospital. The need for the health professional to get on with their work could take precedence over the comfort of the child (7.2).

The Doctor comes in to see cm2.52057. He wants a blood sample and asks "Now or after feed?" The mother answers "now," to get it over and done with and takes the baby out towards the treatment room. The baby still has the bottle in his mouth (15.7.05).

Clinical expediency determined the actions of the staff. The term "best interests" was widely used for times when a procedure 'had to be done' to and for the child despite protestations. Several mothers thought that the promotion of dignity was not possible in some situations when the child's "best interests" took precedence:

"Perhaps it is not always possible when you actually have to do something that they might not want you to do, but you have to do it in their best interests" (mcm6048, this mother was also a non-practising nurse).

Parents wanted procedures to be over and done with as quickly as possible in an attempt to minimize the impact of a stressful and painful procedure. One mother described when a cannula had to be sited in her five-month-old son:

“I think the crying and everything was making the temperature even higher and I think it was urgent to get that (the cannula) in but, I think I had to give him a couple of cuddles to calm him down, but I know you have to, have to have it over and done with as quickly as possible” (Mcm5.12013).

Mcf6042 reflected on the position of babies in hospital:
"You've got to trust the people who've got their best interests at heart, and what they are doing is for the right, because they (babies) are not in a position to help themselves."

The power in the ultimate decision making process is thought by most of the respondents to lie with the medical staff. Even when mcf6042 asserted the need to involve the child in what was happening, she added the caveat:

"...but obviously within the constraints of what they need to do."

Even though parents may have accepted that a procedure needed to be done, they were critical when they thought that it has not been carried out as well as it could have been:

"It wasn't going to be very pleasant for her to have the line put down to start with and it didn't seem to be very organized when it was being done was it?" (mcf14.52004).

The possibility that something was being done that was not in the child's best interest must be difficult to allow yourself, as a parent, to think. Parents relinquished their child and entrusted the care of their child to the professionals:

"I was obviously very anxious, I just assumed that they knew what they were doing and what they were doing was right" (mcf21.12019).

Sometimes even when parents had doubts over the best course of action they felt the decision was made for them:

"They took over and they took it out of my hands" (mcm2021).

7.9.10 Negotiation.

In comparison to coercion, negotiation was sometimes possible where treatment choices were concerned. Mcm6024 talked about her son negotiating the sort of pain relief he wanted:
"One of the important things is that they ask him what he wants, what he feels is best and nothing's really forced too much on him. If he prefers a suppository for pain relief, then that's what he has."

Agreement to be examined was sometimes through negotiation and giving some control to the child:

"It was quite painful, but they said if I say stop, they would stop doing it" (cf11087)

Negotiation was seen to be important at all levels including daily routines:

"I think they should always, whatever the age the child is, it should always be consulted, but I still feel they have a right to say what they would like, try to get the decision between all of you, not just say 'right, well you've got to have your bath now.'" (mcf12006).

Corlett and Twycross (2006) suggest that nurses are insufficiently aware of the power they exert. They suggest that a greater emphasis on the development of the skills required to engage in effective communication and negotiation with families is required within nurse education.

7.10 Witness

Dignity, at one level, is an interpersonal concept (Soyinka, 2004). Dignity and one's sense of dignity is dependent on another or others, a witness or witnesses. The witness can be someone who can see or hear what is happening with another person. The implication of being witnessed is being judged. Throughout the study there was a sense of me watching people, who were, in turn, observing other people, keeping an eye what was going on. This created a sense of watching and witnessing and being watched.

Respondents spoke of their need for confidentiality and privacy from others, I have used the word confidentiality here to mean information, spoken and written, controlled on a need to know basis. I have used privacy to refer to visual exposures. Participants experienced an unease primarily resulting from the 'others' on the ward, or as I have termed the "witnesses". When privacy and confidentiality were not maintained, then the individual patient and family were exposed to the scrutiny of others on the ward, who
became witness to this exposure. This put the sense of dignity of an individual in jeopardy. The layout of the bays meant that others could hear and see a lot of what went on in discussions with doctors. Onlookers or witnesses became party to information in a way that was not useful to the child and their family. Sometimes information was received by accident but on occasions, others seemed to listen and look actively.

7.10.1 Legitimate witness

Some people on the ward, the doctors and the nurses were able to ask questions of children and parents, they were allowed to examine the bodies of children and to discuss them openly without apparent opposition. However, both children and their parents expressed unease at such examinations. One mother rationalized her unease at staff being privy to exposures:

"...the nurses have seen it all before, that the doctors have seen it a thousand times before and it's no big deal to the nurses and doctors" (mcm5.12013).

By this she implied that you do not have to be embarrassed because the witnesses, in this case the doctors and nurses, will not be reactive to what they see. This suggests that loss of dignity is dependent upon the value the witness places on the event and their reactions. However, this is not the full story as mcm5.12013, cuts through the adult platitudes and goes on to talk about her own experience of being in hospital as a four or five year old in Italy:

"I can remember, when I was younger, thinking 'yeah they might have seen it a thousand times before but I haven't seen somebody look at me a thousand times!'"

Cm12088 talked about what it was like when one of the doctors came over on the ward round with "lots of students."

"That's a bit intimidating... They would ask me lots of questions about what I was feeling, mostly I just wanted to be left alone at the time."

Parents objected to the way doctors could appear to disregard their need for privacy and confidentiality when talking about their child, especially during ward rounds:
"On the ward rounds, you know the consultant and ten doctors, junior
doctors, come in with a few nurses and whoever else on the round and they
come in and say 'Oh how is (cm17.12035) today?' and 'what's been going
on?' and if there any other babies, parents in this room, they're all going to
be listening and I think it's wrong for privacy and I don't think they should do
it!" (mcm17.12035).

Even though the staff may be accepted as legitimate witnesses, children and their
families were acutely aware of how staff handled and contained exposures. A careless
leakage of personal information into the public domain could be humiliating.

7.10.2 Exhibits

There were times when parents questioned the legitimacy and motives of some doctors,
usually junior doctors, to ask questions of themselves and their child, as mcm17.12035
described:

"Also to be frank we are a nice case study for a doctor. A bit more exciting
than a splinter! You know 'Pneumonia six times!... But you can see their eyes
light up and I know everyone on the ward has different problems, but I have
seen it, especially when I was in two weeks ago 'Six times!'"

It was as though they interpreted the attentions of the doctor as being one-sided, that
their child did not benefit from the intrusion and yet the doctor did, at their child's
expense.

7.10.3 Parents as witnesses

Parents spent a lot of time, on the ward, with their child. Some of them thought that their
role was important to monitor and watch over their child during their stay, almost as if
their job was to be a witness. Mcf15.12028 described what she thought the role of a
parent was on the ward:

"Just being there, keeping an eye on things."

Moreover, the parents became witnesses to the activities of the ward by default, just
because they were there. Parents, in particular those with a child undergoing
investigations, were sensitive to the eyes and ears of others, including the other parents. When talking about the importance of the dignity of her six-week-old baby boy, one mother said:

"Not having everyone know what's going on, even though you are in a ward environment" (mcm6.52005).

Another mother, of a fourteen-week-old girl (mcf14.52004) said:

"Keeping privacy I guess. Making sure that not too many people in the same sort of ward are looking over your shoulder."

Mcf12006 described the importance of privacy and confidentiality as if they were possessions. When talking about dignity and children she said:

"Whatever they are in hospital for is between them and the doctors and not really for other patients to know about...they don't want other people to hear or to see what's being done. If they want to talk about it theirselves they can do, but at the time of anything being done, it's private."

Parents and older children did not like the uninvited gaze of others. One mother describes how she felt watched and judged by others as she waited in A&E with her baby following a head injury:

"She was screaming so loud, we was in A&E and everyone was looking 'Why don't you feed your baby?' But I couldn't, 'cos I wasn't allowed to" (mcm2018).

It was not just a sense of being judged in some way by witnesses, but also a sense of having to then respond back to their reactions. Mcm17.12035 described how she did not want to have to respond to comments made by other parents in the bay. These were comments in response to what they had overheard during this mothers' consultations with the doctors. They would say: "Oh haven't you had a tough time?" to which she (mcm17.12035) wanted to reply "Piss off."

I have used the term nosiness for this behaviour as this is how it was labeled by the recipients. Nosiness assumes however that the witness had an ill-intentioned motive, but
I think that listening in and watching in some way fulfilled a need to experience what was happening vicariously.

Children too would watch and listen to others and were often allowed to do so by the staff. I noted in my observation record when in Ambulatory Care a child (cm4003) came in for an egg challenge to investigate whether he was allergic to eggs:

*Cm3003 continues to look on, standing very close by – he should be off home now. (The doctor) continues and examines cm4003’s tummy, no screens are pulled. The little boy giggles helplessly as his tummy is felt*” (13.04.05).

I found it difficult when a parent told me information about another child and party to information that I felt was ‘none of my business’. On occasion a parent made a comment to me about another child, such as “how sad” it was about a child who had been run over by a car (19.05.05). I found myself ignoring her comment as it went contrary to finding out a diagnosis unless told by a child or parent directly, it also felt like condoning nosiness and gossip.

The notion of nosiness described earlier caused me some difficulties as a researcher (5.3.3). There were times when to stay and listen to a dialogue, even though consent had been freely given, felt like nosiness. Any knowledge I might have accrued and insights into dignity I might have had did not, always, warrant my listening in to a conversation despite consent. A difficulty, I found with consent to listen and observe that was given freely by the child and parent, was that they did not know in advance what information might be revealed. Sometimes information could be surprising and earth shattering.

Sometimes, staff were able to manage a potential spectacle being made of a child despite the difficult environment of the ward corridor. I recorded in my observations:

*A child that has come in for blood tests (cm6050) is being asked to hop and then walk down the corridor. The mother is looking very anxious. The consultant is smiling and in doing so makes the situation less embarrassing and making it as if the exercise is a bit of fun the child might enjoy. By taking away the seriousness, it somehow makes the scene less of an attraction to nosey visitors (8.06.05).*
Making light of the situation seemed to be an attempt to deflect the interest of a potential witness.

7.10.4 Special needs

Parents and children were usually happy for me to be around (observing) taking notes when they were on the ward and gave verbal consent. They gave consent to take part in a tape-recorded interview without hesitation. However, I noticed that the parents of children with special needs avoided interviews with me. Some were very willing to talk, but did not want to take part in any recorded discussions. I wondered whether I was perceived as just another nosy person to whom they have to recite a complicated history yet could offer no help. I noted in my observation record:

*Cf8050 is an Asian girl with special needs. She does not talk, but communicates through gestures. Her Mum does not seem very interested to see me, but does read my information sheet when I have gone (10.06.05).*

On 13.07.05 I noted:

*Cf6055 has special needs. She has been in every day since Sunday. She still has a cannula in and they are waiting to see if they can go home. I chatted to both of them but her step-mum does not want to be interviewed.*

On another occasion, 21.07.05, I recorded:

*The mother of cm14066 does not want to be interviewed but does not mind chatting. Her son has special needs.*

Although the numbers are small, I was curious why parents of children with special needs reacted differently from other parents. Priestley (2003) identifies the high levels of adult surveillance in the lives of disabled children and their families. Children with special needs are subjected to continuing comparisons with the norm throughout their childhoods. Priestley (2003) argues that the labeling of children as developmentally delayed is to define those who develop differently as: "underdeveloped or incomplete people…‘failing’ to become the kind of autonomous adult citizens that modern societies appear to require" (p.66).
It became evident that parents of children with special needs were irritated when they had to answer the same questions again and again about past history when that information was available in the medical notes:

"Every single time we come in, whatever you go through, there's a standard sort of thing you get taken through. It feels a little irritating, because as an institution, the hospital knows all that information" (fcm17.12035;7.9.3).

The mother and father continued:

M: "But we are asked every time we come in 'Did you have a standard pregnancy? Did you go to term? Were there any..."

F: "Complications...Was he born here?"

M: "We've said this now at least 10 or 15 times."

F: "...or more!"

Perhaps this explains why the parents did not want to take part in any tape-recorded interview, not wanting to become the source of speculation in research. Parents with children with special needs seemed particularly sensitive to the gaze of the witnesses.

In contrast to this, I spoke with two nannies during the course of the fieldwork. They both divulged rather more about the children they cared for than I would have come to expect from parents. I wondered if parents were naturally inhibited from giving away information about their child.

7.10.5 Reluctant witness

As an observer, I was able to see the limitations on privacy, both day and night for the children and their families. I became interested in the reactions and behaviours of the onlookers, the witnesses, to this exposure. I speculated on their nosiness and their gratification from experiencing exposures vicariously. It was almost as if by experiencing an emotion vicariously, they could practice the emotion in safety.

At other times, witnesses were reluctant witnesses, they found themselves privy to exposures or information of, or about, another that they did not invite or want. One girl
and her mother (cf11087) used the curtains to screen out “other children looking awful” as they found it upsetting:

“It was a particular girl who was sixteen and she had her jaw closed so she couldn’t speak, she had a lot of blood, it was a bit distressing. But it was fine – we just put the TV in the way, put the curtain in the way.”

Mcf12080 described her ambivalence when she overheard some bad news being delivered. On the one hand she was appalled at the lack of confidentiality that was afforded the child and his mother and on the other she found herself “nearly hanging off the bed trying to listen”. Because of the condition of her own child, she was not able to leave the bay, nor were there any other distractions around:

“All I can hear is talking about bone marrow and blood tests and transplants, those sorts of things and you think ‘doesn’t sound good’ and then you hear sort of the word leukaemia and then you hear Mum sniffing. I could hear every word and I did not want to.”

Mcf12080 was forced to bear witness to events as they occurred.

7.10.6 Privacy

The children were aware of their need for privacy and described this in terms of the physical privacy of their environment. Mcm14066 said that the side rooms were better than the open ward where you were on show with nowhere to hide away. Similarly Mcm11088 commented that the side room was much better for her son. When I asked why this was so, cm11088 said that it was important to “have something around me, unlike on HD” (He used the staff’s shorthand for High Dependency). It was the exposure that he found difficult.

Children and parent seemed very aware of the eyes and ears of others on the ward. The mother of a fourteen-week-old girl linked privacy in her discussion of dignity and said:

“Keeping privacy I guess, making sure that not too many people in the same ward are sort of looking over your shoulder” (Fcf14.52004).

Privacy was seen as an important way of protecting a child from onlookers. As
ccf8067, who was a carer of an eight year-old girl with special needs said:

“To respect their privacy and not just talk over children. Include them if you can, or if you need to say something privately, obviously make it private.”

The mother of a six-year-old girl combined the need for privacy with a respect for a child’s rights as a person in order to promote dignity:

“Basically that there’s privacy given towards the child: their rights are respected, their rights are respected as a person really” (mcf6042).

There was little privacy in the bays and despite being cited as an important tool to promote privacy, the curtains were all drawn back at night so that the nurses could observe the children while they slept. However, children such as cm14010 did not like other children and parents watching him at night, asleep.

Children and their parents liked the nurses and doctors to use the curtains when they came to do examinations and for procedures. The mother of cf12006 said:

“I think when the nurses come to do anything, take temperatures and things like that, the privacy of the curtains round is very nice and when the consultants or registrars come, the curtains go round so if there’s an examination to be done, then other people can’t see which is brilliant.”

However, privacy could be difficult to maintain. Children coming back from theatre were usually put in the High Dependency Bay, opposite the nurses’ station. Certain medical conditions made privacy and ‘covering up’ difficult. The halo traction for congenital hip dislocation was described by mcf15.12028:

“She was strung up by her legs and then each day, it was moved a certain degree and so her legs were getting further and further apart and that wasn’t particularly nice changing nappies.”

However, some of the children put up with the limited privacy and liked to be on the open ward where they did not feel isolated:
"It was nice to hear loads of sound, 'cos usually its very quiet and there were like little kids and everything, it was nice to hear some sound" (cf12006).

Children with repeated admissions were routinely cared for in side rooms if they could be neutropaenic. The children in the side rooms seemed to appreciate their privacy and those who had been in several times seemed especially sensitive to onlooking children and their families. Cm12088 described what being in a private room meant to him:

"Not many people coming into the same..., having something between you and other people, being in your own personal space."

When children who looked different were not placed in side rooms they attracted attention. The carer of cf8067, who had complex needs, commented:

"Other children do stare and look and yes I think she deserves a bit of privacy."

Likewise, cm11047, preferred not to have other children around him as he said they were "always pestering" wanting to know what was the matter with him.

7.11 Performance of dignity

I have described (6.11) how dignity was promoted through ritual and stylised behaviours by the staff. I have called this the performance of dignity. Dignity was operationalized by staff and maintained through rules and the use of ward articles that I have referred to throughout the thesis as "props".

7.11.1 Dignity props

Dignity props included curtains and gowns. The effectiveness of props in promoting dignity was, in part, reliant upon a shared meaning of the use of these props between staff and parents and their children. In adopting a symbolic interactionist approach to my analysis as described previously (3.5.4), I have assumed that people attribute meaning to props derived from social interaction and modified through interpretation. I was interested to see how meaning was interpreted by children, as the meanings of curtains and gowns and other props, I argue, were largely symbolic and context specific.
7.11.1.1 Curtains

Some young children appeared to understand how the dignity props were used. Mcf6042 described how her six-year-old daughter would remind her: “Curtain round” when she was putting on her jeans to identify a private space.

Parents appreciated shows of respect, as one of the mothers said:

“The privacy of the curtains round is very nice and when the consultants or the registrars come, the curtains go round so if there’s any examination to be done the other people can’t see which is brilliant. Here they’ve done it every time and I think it is important for anyone, child or adult, to have that bit of privacy” (mcf12006).

Some children recognized that the curtains did not create real privacy and although they were drawn their use was largely symbolic. Cm12088 was in a side room but spoke of how he would use the curtains at another hospital:

C: “You could hear everyone else"
R: “And they could hear you?”
C: “Yes.”

Mcf6042 mentioned how she appreciated the use of curtains. When asked in what ways, she acknowledged that curtains do not keep everything private but described the value of curtains in their symbolic meaning:

“I suppose you don’t feel that you’re telling everyone, even if you don’t want to. I mean noise carries, sound carries quite easily, but it just gives you that closed cocoony bit doesn’t it, a little shelter, so you’re less exposed.”

The curtains did not keep the noise of conversations in, nor maintain privacy, but the meaning of curtains derived from interaction and interpretation resulted in a feeling of privacy. In this context the feeling of privacy and refuge from witnesses was paramount. It was not only for the benefit of the patient undergoing a procedure that curtains are used as illustrated by the story told by mcm5016:
"There was a little girl who had to have stitches taken out and she was going mental, she was upsetting the whole ward so they took her off into another room."

The well being of the rest of the ward was affected by the uncontainable child's cries.

However, when the meaning of props and cultural artifacts, such as gowns, were not understood or shared by children, distress resulted. For example the role of a theatre gown and its meaning in keeping the naked body covered and in doing so promoting dignity, was not always appreciated by the children. Indeed several of the children found it demeaning to have to wear a gown. One boy, aged five and a half, had come in for a tooth extraction, afterwards he was angry and tearful at having to "wear a dress" (cm5084). Wearing a "dress" could have been a trigger, rather than the cause of this child's anger and tears. Nevertheless, other boys (cm12066; cm14039) expressed a dislike of the theatre "dresses".

7.11.2 Costumes

Uniforms were used by nursing staff to protect their own clothes and to denote role and rank. White coats were rarely used by doctors on the ward, although sometimes worn by junior doctors. Theatre staff wore theatre dress and were commonly seen on the ward collecting children or bringing them back from theatre.

Some parents and children did not like uniforms. Cf12080 had complex needs and found communicating difficult, but she did not like white coats. Her mother acknowledged that uniforms were sometimes required, but felt that the uniforms could set the staff apart and be worn for the benefit of their egos. She said:

"There are times when you need white coats. Nurses they've really got to be in uniform, but with white coats, stethoscopes and all that kind of thing, they are all up their own backside quite frankly and they need a good slap and brought back to earth."

This mother felt that uniforms alienated staff from the children and their parents and vice versa. She interpreted that for some staff, the uniforms gave them a sense of superiority.
7.11.3 Rules of dignity

The way dignity was performed by the staff was, to an extent, co-constructed with the parents. Parents described how they contributed to the promotion of their child's dignity whilst on the ward. In determining how children should be cared for, in terms of promoting dignity, parents used the "as if" principle (7.7.4). Children were to be treated in such a way as to respect their dignity as if they had full awareness of the social rules and norms of dignity. One mother described how, as a parent, she could compensate for the limitations of an infant in safeguarding dignity:

"You can still wrap round the curtains and I think that is fair enough to do, but still do the measures that you would do for any other aged child, but obviously you would have to do more work as an adult than the child would" (mcf6042).

Parents reflected on how they behaved with their child in order to convey their respect and promote their child's dignity. One mother (mcm11.12064) explained how she would demonstrate respect for the autonomy of her 11-month-old son:

"When I changed his nappy I say, I am changing his nappy. I don't know it's just that I do explain things to him, I do try to talk to him, I suppose to communicate with him rather than just make decisions for him all the time."

Mcm6024 explained how a baby might be treated with dignity in hospital:

"You know nice clothes and so forth, rather than just leaving them undressed under a sheet or something, would be nice."

She continued:

"...but I'm not sure if that's to do with the adult's perception of how the child should be...the dignity that the child should have, or for the child's benefit, I don't know."

Although it was an unwritten rule, the children had to dress appropriately for their environment as described by the mother of a fourteen year old boy (cm14010):
"I think he has to respect that there is a dress code and that making sure that he is actually respectable in the way that he is within the hospital environment. No boxers."

She described the way that her son had to suppress his choice in what he wore and his individuality, in order to fit in and not cause offence to others by exposing too much flesh.

7.12 Emotion work - The manner of performance

It was apparent from the interviews with the children and their parents that the way they were treated by the doctors and nurses was as important as what they did. When asked about dignity, both parents and children stressed the importance of the way they were treated and spoken to. The manner in which staff performed their role and the quality of their interactions with them was important to both parents and their children. It was as if in their manner they were able to evoke a sense of well-being or positive feelings. As the mother of cm5.12013 said:

"That softly softly approach is so important" and "Smiley, nice, kind nurses are...make all the difference you know...It just takes one nurse or one doctor or someone, to be having an off day for a child to remember."

Theoretically this manner of performance can be related to emotional labour (2.2.7). Hochschild (1983, p.7) in her analysis of the work of flight attendants describes emotional labour as the suppression, or induction of "feeling in order to sustain the outward countenance that produces the proper state of mind in others...the sense of being cared for in a safe and convivial place." In the example above, the parent recognized that for the child to feel cared for the member of staff cannot be having "an off day", they must in their capacity as nurse or doctor, suppress their own feelings in order to induce feelings of being cared for in the child.

Outward presentation of self, by the staff, was important and commented upon by parents and children. Mcm4052, the mother of a four-year-old boy whose condition had necessitated long treatment, interpreted smiles as "friendly." She said:

"...smiley staff, friendly staff for both children and parents."
Smiling was mentioned by children in answer to what would they like their nurses to be like:

R: “And if you had to have nurses, what would they be like, would they be...?”
C: “Nurses I know and smiley nurses” (cm8079).

The way, or manner the doctors and nurses went about their work had a clear affect on parents and their children on the ward.

“...not having loads of people not looking terribly serious around you. Even if it is serious, I mean I know it’s difficult, 'cos if you are doing a serious job, you know, you can’t be wearing a clown’s uniform and a funny nose” (mcm5.12013).

In the example above, the mother expected and desired a manner that was not overly serious, yet remained congruent to the situation. A clown’s uniform and funny nose would not be appropriate.

Hochschild (1983) differentiates between “surface” and “deep acting.” An example of surface acting would be to put on an expression, such as smiling, in order to make our inner feelings correspond to how we appear (Smith, 1992). Deep acting, is from the inside to the outside. Feelings are induced that in turn change our presentation of our selves. Parents thought that the way staff acted and worked was paramount to even the youngest children:

“But there is no reason why you shouldn’t go ‘Hello Baby Smith or ‘Hello darling, hello love, hello Babes, all those sort of things, so that again 99.99% of babies are going to hear. They hear soothing, they hear pacifying so that’s reassuring...” (mcf12080).

How children were treated was thought important in promoting dignity. The way children were treated was dependent upon the emotional labour of the staff and how well they were able to manage their own feelings in order to promote a sense of well being in the child:
"How they are treated by them, tone of voice, the way they comfort them" (mcm6.52005).

Parents understood the way staff performed their role as something more than just an act, but interpreted it as an indication of their character and ethos. The mother of cm5016 described what she thought the nurses needed in order to carry out their role:

“You have to have an approach to life that lets things go the way they are going to go and if that kid is freaking out to say 'Leave it, we're going to do it another time.'”

In order to bring off a performance, an actor has to use his, or her body, in a way that the audience will perceive him, or her, to be authentic and have confidence in them. The manner of their performance has an impact on the relationship with their audience. Likewise parents on the ward commented on the way staff behaved. Subtle and not so subtle messages were communicated through the use of their body and voice. Parents did not like to be cared for by staff whom they did not see as credible, or somehow lacking in professional integrity. Parents adopted the role of witness in making judgments about how the staff performed. One father commented:

“I think we have witnessed a lot, or a couple, of girls who are in training and they are completely unaware of what they are supposed to be doing in certain cases.”

He continued:

“I think it is unfair for them to be in a situation, in front of patients, where they are not up to speed on everything” (Fcf14.52004).

The students did not seem to have been able to bring off their performance in a way that induced confidence in this father. I could speculate that they were not able to manage their own feelings of uncertainty and unpreparedness sufficiently to instill confidence in the parents. In particular, the parents who were used to the hospital and the routine were quick to watch the performance of the staff and form opinions:

M: “And you soon get to know the nursing staff, the students (student nurses) who are going to be any good and who is really wasting my time, in about ten minutes”
R: "Can you give me an example of that?"
M: "Well you get the ones that go (mumble mumble) like that or you get the others that go "Hi my name's Anne and I'm going to be looking after ...for this shift and I go off shift at 9 o'clock and ..." (Mcf12080).

The way staff presented and conducted themselves at a wider level, including with their peers, influenced what parents thought of them. If they:

"demonstrate(d) professionalism at all times and friendliness towards each other then you get a great deal of faith and confidence in that, that 'H' she's nice, I don't mind her looking after my child tomorrow' or 'She's really nice, go and ask her'" (mcf12080).

Staff were on show and in the public domain, throughout the ward. Only the office, and to a lesser extent behind the "wall" (5.2.6), separating off the nurses' station could the staff have some of the privacy and relaxation associated with being backstage (Goffman, 1971).

7.12.1 Emotion work of staff

Parents seemed to recognize an emotional component to the nurse's work (6.12). Parents thought that staff should be able to use their emotions to assist them in understanding and caring for the children and families in their care. I found I was able to replicate the codes used for the way staff described how they managed their emotions in promoting dignity.

7.12.1.1 Tuning in (6.12.1)

One mother (mf15.12032) thought that nurses needed to be able to "tune in to each of their patients and their families". Another mother said that the staff needed to:
"(think) about what they would want if it was their child, or if it was them in that situation" (mcm6048). Tuning in here seemed to relate to the notion of empathy. Rogers (1961) held empathy, or empathic understanding to be one of the three core conditions of a therapeutic alliance. His meaning of empathy was the "capacity to track and sense accurately the feelings and personal meanings of the client" (Mearns & Thorne, 1988,
Mcf12006 seemed to suggest tuning in, or empathy, as a skill staff could use to promote the dignity of the children:

"I think they should put theirselves in our shoes and it’s like if that was their child, what would they like for that child."

It was as if parents wanted staff to recognize the shared humanity and commonalities between them and the children and their families by "tuning in" rather than distancing themselves.

7.12.1.2  Moderating (6.12.2)

The staff described times when it could be helpful to hold back in their dealing with children and their families, by allowing time and space. Staff had to suppress their own emotions and urges to get the job done. This sense of moderating by understanding the child and correctly pacing what needs to be done, was appreciated by cf14047.

"All the doctors and nurses are really kind and helpful, they are not like pushy or anything at all."

Appropriate moderating of themselves and their emotions was described thus by the mother of a twelve year old girl (mcf12080):

"They have got to have a quiet faith in themselves. They have got to go in with a confident manner, but not 'I'm a nurse, I know everything up yours.'"

7.12.1.3  Detaching (6.12.3)

The parents of cm17.12035 felt that staff reacted to them and their child in the context of having seen worse before, that although they connected, to some degree, with their anxiety and pain it was all relative:

"...as a sense of what you as a family are going through, and there are occasions when we have a sense of, where doctors or nurses seem fairly, you know unpleasant, they see children and families with harrowing stories every day, so you're just another one" (mcm17.12035).
Parents recognized the demands on staff and thought that:

"It must be difficult, day in day out, to be understanding," but continued: "You notice the difference between people who make you feel either they understand that you are having a hard time, but they are doing everything they can to ease that...but there are other people who you just feel you are interrupting their general flow of work" (fcm17.12035).

This quote demonstrates the complex web of emotional work on the part of the nurse to induce a sense of being understood, but also in the work of the parent involved in evaluating the demands they and others make on the staff.

7.12.1.4 Integrating (6.12.4)

Integration applies to the way some staff seemed able to incorporate different aspects of themselves into their professional persona. They were able to relate, in a direct way to the children and families without the trappings of their professional role. Parents appreciated staff getting to know them and their children as people. Mcm2021 described what she liked about a group of nurses she had got to know at a different hospital during her son's stay:

"They were so down to earth and didn't treat you, you know they treated you just like another person they got chatting to at the bus stop, not like someone you had to say, you were an inconvenience, the nurses, the younger nurses, seem to just not have a human side to them to me."

Mcm2021 implied that the group of nurses from the other hospital demonstrated their humanity by relating to them as an equal. The "younger nurses" she described seemed more personally distant as though their humanness was held apart from their work as a nurse. She continued:

"I think they are scared of putting a foot wrong, or saying the wrong thing, so they don't say anything."

She described how rather than taking the risk to show and acknowledge a shared humanity, the nurses had held back of themselves too much.
The mother of cm8079 appeared to recognize the emotional labour of staff. She spoke about how staff could work with their own emotions to recognize the needs of the child and hold on to their own anxiety to hurry up and attend to others elsewhere. This she felt was key in honouring the dignity of her son:

"I guess the trick is for them to make him feel that he is the priority, they have got time even when there isn't. If you can give every child that, you have succeeded. It's not always possible, but it seems he feels rushed, he feels pressure and he loses confidence" (mcm8079).

She used the word "trick" in a way that emphasized the work and expertise involved.

7.12.2 Emotion work of parents

Parents spoke of their position between the medical staff and their child (7.5). They reflected upon the emotionality of this relationship:

"...supporting the medical staff, trying to get them together, I mean its difficult when...it's the parent thing, 'cos you've got the emotive, the emotional side which you don't have on the other side and I think that's very, that's the very difficult one" (mcf6042).

This mother emphasized the emotional nature of her work as mother, rather than acknowledging any emotional component to the relationship for staff. Parents spoke of how they worked to control their emotions as a way of maintaining a calm atmosphere and preventing a contagion of anxiety to their child. Mcf14.52004 said:

"I was nearly crying whilst she was having it done, but I turned away because she could not see me getting upset 'cos I didn't want to stress her out and I think if a child could see parents getting a little bit worked up about anything it's going to rub off on them and they could end up getting a little bit panicked."

They described the intensity and relentlessness of their role as parents resident with their child. The mother of a six-week-old boy described her situation:

"There's no escape and it does feel like it's getting completely far too much...we have left him once, but even then you are away and you just constantly want to get out because you worry about him" (mcm6.5205).
This mother had another child at home, who was seven, and this created additional feelings of being torn.

Parents spoke of how they experienced a range of emotions as they explained to their child about procedures. Mcf15.12032 talked about preparing her child for a lumbar puncture:

"It was a bit emotional, but you sort of go on this roller coaster, where you think, you know, this has to be done for you, this is good for you, I love you and you are not going to remember it necessarily. There's going to be lots of hugs afterwards and it's going to make you feel better."

Her description illustrates the intensity of her emotions and her struggle to interpret and manage them for the best outcome for her child. By working on themselves in this way parents were also able to better tolerate the pain of their child.

7.12.3 Emotion work of children

Some of the older children were able to describe ways in which they managed their emotions. One fourteen year-old-girl (cf14047) described the way she felt compelled to behave in a certain way for the sake of the younger children, an example of emotions work:

C: "I know it sounds stupid, but I feel like I have to be strong 'cos I don't want them to think that it's really bad."
R: "You wouldn't want to cry in front of them?"
C: "No."

As all the interviews with children, except one, were undertaken with a parent present, they may have felt constrained talking about issues and may have wanted to protect their parents (Bluebond-Langner, 1978).

7.13 Being Human

It was evident from what children and their parents said that they appreciated the relationship with their nurse or doctor. The children and their parents described how, in establishing a relationship with staff, the humanity of children, however young or
disabled was recognized and acknowledged and for staff then to engage actively with them. Feeling as though they were treated with dignity and their sense that their dignity remained intact was integral to the relationships they were able to establish with the staff.

7.13.1 An individual approach

The idea of being treated as an individual and as a person was inherent in the concept of dignity for some of the respondents. Mcm17.12035 described what she thought dignity meant:

"Being explained to what’s going on rather …than just being processed…as an individual, a person."

One mother of a six-week-old baby, conjectured that it could be possible to forget the individuality of very young children:

"I suppose with very young children, you could become blasé of how you go from one to the next, forgetting that they are individual people” (mcm6.52005).

Parents were appreciative of efforts to get to know their child on an individual basis:

"Every child is not just another case…it’s been (child’s name) we have been dealing with not just a case number with a dislocated hip” (Mcf15.1228).

Mcf15.12028 went on to describe how the nurses had cared for her child unconditionally and hinted that it was the individual character of her child that staff might ultimately find rewarding:

"She is quite a difficult character. The nursing staff are caring and it didn’t matter what she did, they came back you know, which I know is their job, but they could have come back with a bit of an attitude at times. And no-one got cross with her. They loved her for her little character."

Children liked nurses who made the effort to get to know them and showed interest in them as people. These two examples are from twelve-year old girls:
"She made conversation all the time and asked about...and got to know me and everything. So when we talked about something she'd say something to me about her life and we just talked for ages" (cf12006).

Similarly cf12030 said: "In here they are really chatty and they talk to you about your hobbies."

Older children appreciated being spoken to directly instead of through their parent. Cf14047 spoke of her experience in the hospital:

"That's good the way they talked to me, instead of talking about me to my Mum, that helped a lot..."

She contrasted this to her experience of her GP when:

"They tell my Mum about my medication and stuff"

Two parents (mcm17.12035 and fcm17.12035) had been surprised by the humanity of the consultants and the genuine liking of the children:

"Yep, all the consultants are on first name terms and they seem to ummm, it's not just being an interest, but they do seem to really like children!"

### 7.13.2 Time

Time, both lack of it and too much, was important to the children and their parents. Several of the parents referred to the ward being “busy” or “quiet”. They were very conscious of the level of activity on the ward and had no doubt how this impacted upon their well-being. On the whole they did not like to see the nurses “rushed off their feet”.

"It's nice that they have had a bit of time and haven't been rushed off their feet" (mcf12006).

There was a sense of the patients waiting and the staff being very busy elsewhere (6.3.3.1). The mother of cf6042 spoke of her daughter’s admission to the ward through the Accident and Emergency department when it was busy:
“It got really busy, but no it was just the sort of waiting around that really, that’s what’s difficult and then equally when we came up to the ward we had quite a long time to wait.”

When asked whether it was always possible to provide the things that are most important for a child in hospital, mcm2018 replied:

“Not always possible because they are always busy doing everything else, the nurses, it’s quite difficult, ‘cos they haven’t got enough time, so busy rushing around everywhere. They have got to get it all done quickly. Maybe it’s too quickly for the poor little things.”

Thus lack of time and busyness of staff were seen as potential threats to the well-being and dignity of the children and parents. Having to wait their turn and others taking priority had the effect of disempowering the children and their parents. Children described waiting while others took priority:

“There were more emergencies so mine had to wait because it wasn’t that serious” (cf11087).

However, the waiting and prioritising was not always explained to the children and their parents. Cf11087 continued her dialogue with her mother about her wait for her appendix to be removed:

M: “They (other patients) just walked in.”
C: “They just walked in happy as anything.”
M: “Half an hour later they went out and came back.”
C: “They went home that day.”
M: “They went home before your operation....”
C: “So it was a bit sort of annoying ‘cos I felt like I’d been waiting.”
M: “She was upset.”
C: “And it didn’t look like they were in quite a lot of pain.”

Other times patients felt reassured when explanations were given by the staff, despite having to wait:

“...they made a point of coming to see us and just sort of introducing themselves, so then you were left for a bit, but at least you didn’t feel like you were being totally forgotten” (mcf6042).
It was clear that when children and parents felt that they were given the time they wanted they really appreciated it. To be given time was interpreted as being worthy and as if they mattered. Mcm8079 described the approach of the nurses at another hospital, to get over her point about the value of time and the use of time in hospital:

"(They) are very very specialized and are trained in that way. I have never, in three and a half years ever seen one of them rushing. They always seemed that they have plenty of time and plenty of reasoning power and nothing is going to rattle them and I think this is great skill that people underestimate in nursing. Because it is quite easy to sort of keep on looking at your clock and saying, you know, 'I have got a baby that needs his feeds and I haven't got time', it's easy to do that when you are under pressure."

Her insightful observation questioned the inevitability of the nurses being too busy and suggested the management and the quality of the time given to be paramount.

7.13.3 Stigma

Goffman (1963) understands the acceptance of others as central to the self-identity of an individual. In his analysis of stigma, he positions the body mediating the relationship between self-identity and social identity (Shilling, 2003, p.75). Thus the negative reaction of others, the witnesses in this case, can spoil identity and result in stigma (2.2.6). Shame is the emotion associated with stigma and stigma seemed, from the fieldwork to be something that was shared by the family of an affected child. As I have demonstrated, some of the parents were very sensitive about what was wrong with their child, they seemed to experience a sense of stigma related to their child's condition. Mcm17.12035 described the different needs for privacy between a child coming in with a splinter and the mother of a child, such as herself with a number of medical problems and complex needs. She found the lack of privacy painful and "disgraceful". She continued:

"It's not private you know. 'Anything you'd like to tell us about?' 'No I'm OK I've got a splinter in my toe', but you know his problems are..., I don't want to be discussed in public, I am very private and I don't want it."

One mother of a child with complex needs spoke of how she tried to be seen privately for out patient appointments. She thought that the difference between the private sector
experience and the NHS had lessened over the last twelve years. Nevertheless, her remarks were damning:

“The impression one had of an NHS was you are lucky we are seeing your sick child, it really should have been put down at birth” (mcf12080).

A sense of dignity and the stigma of a damaged embodied self identity would seem to be mutually exclusive. Equally there becomes apparent a dissonance between a shared humanness and differentness. “Stigma signals”, such as naso-gastric tubes may signal and contribute to difference. Goffman (1963) discusses the obtrusiveness of a discrediting attribute as important and individuals work in stigma management and the negotiation of a spoiled identity.

7.13.4 Objectification of child

Children and their parents were sensitive to the way staff dealt with and related to them. They appreciated staff who demonstrated interest in them as individual people. A sensitive approach to the child was seen as indispensable:

“I think that all that softly, softly approach is so important, if at all possible” (mcm5.12013).

In contrast, some of the parents spoke of how staff appeared to disregard the humanity of their child and of their child being treated as an object rather than a child. In my interview with the parents of cm17.12035, they described a procedure of their child: “He had to be pinned down to the bed!” “The table,” corrected the husband as if to accentuate the depersonalization of the event. As they spoke, “the table” conjured up an image of an operating table or even a sacrificial table.

One parent made a candid connection between objectification of her child, in this case her baby, and an insult to their dignity:

“If people are performing some kind of medical procedure on your child, on your baby, who obviously can’t understand, but they are talking about their weekend at the same time, or giggling about some joke, then for me that’s an insult to their dignity” (mcm2021).
Two of the mothers described how their child was reduced to body parts for venous access:

"These registrars didn't even look at L. they were just looking at his arms and how they could get the blood and I felt that his dignity was really insulted at that point" (mcm2021).

A similar event was described by another mother:

"So the antibiotics weren't going in so they had to redo a line, and it became harder and harder, as you start looking at hands and feet and where else is it going to go" (mcm17.12035).

These descriptions of events demonstrate how focusing on the task and judging outcomes by procedures accomplished, can result in the objectification of the child.

7.13.4.1 No heed

Related the notion of objectification of the child was the way 'no heed' could be taken of the child. Despite the purpose of the hospital stay being to help the child. It seemed that sometimes no heed or notice of the child was taken. Instead the focus of the work was to fulfill the agenda set by the staff.

Mcm2021 talked about an early admission with her child when he was a baby:

"There are particular things that babies need: sleep, food at the right times and things like that. And I felt that the occasions when I was most upset was when there was no heed taken of L. The fact that L. had just dropped off to sleep, having been kept awake all day because he had had this test and that test and everything. I understand that this is a busy hospital, but I think more heed could have been taken of the fact that he hadn't slept for ages and he was about to drop off and then you'd be waiting and waiting and waiting and being told not to feed him and keep him awake because this was going to happen and he would drop off to sleep and then on one occasion it was three in the morning when the registrars were free to come and take blood from him. He was woken up at three in the morning and taken to a bright room."

Mcf12080 shared a comparable example, where the member of staff seemed to ignore both the patient and, in this case, the parents. The mother described how, at an out
patient appointment, she explained to the doctor that her daughter reacted badly to personnel in white coats. The doctor disregarded this and continued with what he/she was saying:

"She (cf12080) really goes into one, we needed to suction her, so we are trying to suction her, she's gone really stiff and the doctor doesn't stop talking about what they are going to do and I can't even hear 'cos the suction machine is going and she is throwing herself off my lap."

Twelve-year old cf12006 described how a doctor took blood from her arm even though both hands had been prepared with local anaesthetic cream:

"They put the numbing stuff on my hand, on like both of my hands, then like they, the doctor went and took blood out of my arm, 'cos they couldn't find a vein on my hand. It was on my hand for ages and then they went and took it without the numbing stuff!" (cf12006).

No heed can be equated with the notion of not giving respect as suggested by mcf4.12007:

"You wouldn't just barge in on an adult and start doing something without asking their permission first. I think it is important that children are given the same respect really."

The centrality of the relationship is key to the philosophy of Rogers (1951;1961). For Rogers the core conditions of unconditional positive regard, empathy and congruence are both necessary and sufficient for a therapeutic alliance. Children and their parents valued their relationships with the staff. Fundamental to relationships was a recognition of the humanity of the other, "being human", no matter how young or ill or disabled. Acknowledgment of the individual child could be as simple as using their name and addressing the child directly. Finally children, and their parents liked to be engaged in the process and participate in discussions, choices and care.

The staff, and nurses in particular, also found relationships where they 'got to know' the children and their families rewarding. These relationships were characterized by some a feeling of reciprocity (6.5.1.1), with children and parents recognizing the humanity of the staff member, acknowledging that they were busy and empathizing with the pressures of work, seeking to engage them by being undemanding and 'good' (7.5.3).
Children and their families could feel objectified when the pressure of tasks overwhelmed the staff members' capacity for the emotional work necessary to initiate and sustain a mutually rewarding human relationship. Busyness and the anticipation of overwhelming demand could result in distancing tactics by staff, such as when new patients arrived on the ward.

Summary of Chapter Seven: The Voices of the Children and their Parents

In this chapter, I have presented my analysis of the findings from the children and their parents. In the first half of the chapter I have concentrated on the context of the research from the perspectives of the children and their families. In the second part of the chapter, I have focused on their meanings of dignity.

The importance of the total environment of the ward to the children and their parents and how this influenced their sense of dignity was apparent. Throughout the interviews respondents reflected upon the "strangeness" of the environment they found themselves in. Both children and parents craved a sense of normality and their own routines, and struggled to make sense of the strangeness that surrounded them. The parents and children were wrong footed by their immersion in this alternative culture that rendered them disadvantaged.

Child patients in this, the main study, had a parent or carer for most of the time during their stay. Changes in the role of nurses caring for children and an emphasis on children being treated in hospital for a short a time as possible underpin these developments (2.3.3). Medical and nursing care in recent times has become indirect and more focused on the importance of the child and family in a triangular relationship or triad. Communication was paramount in terms of demonstrating respect for the child. Parents were clear that their child could communicate even if they did so nonverbally. It seemed that some children found communication more difficult because they were less likely to be listened to, such as the very young and those with special needs. Staff, it was felt, were more inclined to make assumptions about such children rather than working to understand them.
Parents spoke about their perceived need to protect their child and children themselves spoke of defending themselves against the medical team. Parents saw their role as advocate. Sometimes they adopted this role under duress and some would have preferred to have been able to entrust the care of their child to the medical and nursing teams.

Parents wanted to be seen as good parents and were anxious not to be labelled 'difficult' in case this affected the care of their child in a negative way. The data suggest that parents may well put up with limited privacy and less than adequate explanations, just because they want and need to keep the doctors and nurses on their side.

If parents were too compliant with the requests of the medical/nursing staff then there was a risk that the voice of their child could be overridden. Some parents of children with complex needs seemed disillusioned with some of the care they received and assumed a critical stance against the staff. Others had adapted to the system and developed strategies for receiving the attention they required.

Parents worked hard to control their emotions, to maintain calm and contain the anxiety of their child. They spoke of the intensity of their role as resident parent. Parental presence sometimes altered the dynamic between child and parent. Parent and child were often physically very close and spoke in terms of emotional and almost visceral connectedness.

Prior to admission parents and children had to demonstrate the legitimacy of their ill health. They did this through verbal history and conceding to measurements and tests as requested by the doctors. Legitimacy was demonstrated by admission and relinquishing of the child by the parent to hospital care. The insertion of a cannula and the taking up of a bed on the ward or side room rather than in Ambulatory Care which was a transitory or liminal space, was symbolic of the child's illness.

Inherent in the total environment, or vibe, were the power relations between the staff and the children and their families, and to a lesser extent the 'other families' that took on the role of witnesses. Respondents talked about the vulnerability and passivity of their child in relation to the power of the staff during hospitalization. Arguably this also reflected the
position in which they found themselves as parents when they relinquished their child to
the care of the professionals. Parents and children recalled different ways of delivering
care ranging from coercion and acting on the principle of 'best interest,' through to
negotiation.

The parents constructed their child as just that, 'their child'. There was a degree of 'them
and us' exhibited between the children and parents who were there for short stays and
those who were in for longer or frequent stays. Although parents and children
appreciated seeing familiar staff they did not say they were 'pleased to see them' in the
same way the staff had.

The measurement and testing of children conjures up a notion of 'the normal child' as a
'gold standard'. Children who did not meet the expected measures differed from this
norm and were constructed as something other than normal. For many children this
process started at, or before, birth and parents struggled with this reconstruction of their
child as a 'child with complex needs' or with a particular diagnosis such as cystic fibrosis.

The children identified themselves by age. They appreciated being near those of a
similar age. Teenagers expressed different needs to toddlers and caring for both in the
same bay could lead to conflict. Parents constructed a child according to their age and
carried assumptions about what a child of a certain age might want, or be embarrassed
by, or understand.

Boys spoke of some of the things they found embarrassing in hospital such as hospital
gowns and being cared for largely by female staff. It seemed that their gender and
sexuality went unacknowledged. The girls and parents did talk about staff
acknowledging them as girls and young women and recognized that the staff attempted
to counter potentially embarrassing events or procedures.

The children were constructed as discrete units. They were separated out on beds and
were not actively encouraged to spend time together. The children did interact together
with their parents and this was largely on their own instigation. Children were not
introduced to one another as a matter of course.
Children appreciated the Playroom where they could play away from their bed space. The older children (from 6 years upwards) thought there could be more for older children and that the facilities were better suited for younger children. Boredom was a factor for children who were in for prolonged periods. They expressed the loss of outside relationships with friends and family and every day living, resulting in boredom and a state of ennui.

**Part II: What does dignity mean to children and their parents?**

Responses from the parents about the meaning of dignity associated the meaning of dignity with the value of the individual child and demonstrating respect. Their responses as those with the staff interviews could be categorized as value based definitions, intrinsic dignity and physical definitions, extrinsic dignity. Often both types of definition were included in a response.

Although they saw dignity as a constant, parents thought that children became more aware as they got older and more easily embarrassed about bodily exposure. This was confirmed by some of the older children. Parents thought that children had dignity, even when they were very young. They acknowledged that they may have limited awareness of such, but thought that they should be treated ‘as if’ they did have such awareness. It also seemed that by treating a child as if they had awareness of dignity, the staff were reminded of the value of that child in the eyes of the parents.

Parents thought that dignity, or at least the social norms of dignity, such as bodily exposure, were learned, through role modelling from the parents principally. They suggested that nurses had a part to play in establishing appropriateness of behaviour and dress in the ward environment.

Children and their parents both thought that bodily awareness changed as the child grew up, with young children unembarrassed about bodily exposure and nakedness. Older children described their embarrassment at bodily exposure and of wearing what they felt to be inappropriate attire such as theatre gowns, or seen in inappropriate ways such as on a hospital bed rather than walking.
Children experienced pain from their medical conditions and procedural pain. Of particular and common concern to children was cannulation, both the procedure and the restrictions associated with having a cannula in situ. Health care professionals did seek to find out about the children's pain, but their preconceived ideas about the level of pain the child was experiencing that could affect what they heard from the child. Local anaesthetic was not always used prior to cannulation. The touch of the health care professionals became associated with discomfort.

Children and parents were very sensitive to the eyes and ears of others. This was particularly true for children with conditions that warranted repeated or prolonged hospital stays, or had complex health needs. They felt judged and did not like having to respond to the uninvited attention of others. Children were aware of bodily difference and something of the affect their appearance had on others. The appearance and ableness of a child's body had profound effect on the embodied existence of the child.

Doctors and nurses were allowed access to the bodies of children for examination and to their stories. On occasion, the legitimacy of the staff were questioned when their motives for intrusion were suspect, such as when their interest in the child appeared to be as a medical curiosity, rather than in an attempt to help. Repeated questioning was also disliked.

Parents and children appreciated attempts to maintain privacy and confidentiality, either through the use of curtains or through the provision of more private areas such as side rooms. Some parents reported their unease at witnessing something that they felt to be private and not appropriate for them to be exposed to.

In this section I have explored how dignity is performed from the perspective of the parents (the audience) and children. In contrast to the staff, they were less concerned with the correct and appropriate use of props such as curtains and gowns and more concerned with the way or the manner in which dignity is honoured. Parents and children appreciated smiles and courtesy. They understood the manner of the staff as more than an act and valued authenticity, time and professional integrity. They did not like the sense of an unequal power relationship, but wanted to engage with staff on a equal human level.
The meaning of dignity props was, in the role of maintaining social norms of extrinsic dignity, understood by parents and children on the whole. Younger children had a more limited understanding of curtains and gowns and their symbolic meaning and as a social construction. Parents and children put less emphasis on the need for props in maintaining a sense of dignity and greater emphasis on the human capacity of staff.

Parents recognized that emotions and their management played a part in the role of the staff. They also spoke of their own emotion work in relation to ‘doing dignity’. Some of the older children too were able to reflect upon their own reactions and emotions and how they worked to contain and manage these in the ward environment.

Parents and children appreciated an approach from the health care staff that acknowledged their humanness. They liked to be recognized as individuals and the staff getting to know them as such rather than just being “processed.”

Time for children and their parents was an important factor in their experience of hospital. Several described long periods of waiting while staff were busy elsewhere. They were very aware of the level of activity on the ward and the busyness and thus availability of the staff. Parents and children appreciated when time was given to them especially when the time was exclusive to them, it made them feel acknowledged.

Some of the parents with children with complex needs found the limited privacy available to them difficult. They resented junior staff treating them as new arrivals and having them retell a long and difficult story, often in the relatively public space of an open ward.

There were occasions when parents felt that recognition of ‘being human’ had not extended to their child. Parents and children themselves spoke of times when they had been reduced to a body on which to perform a procedure. They recalled times when the staff did not seem to connect with their own meaning and the seriousness of the situation by chatting to one another about something else. Both children and parents talked, with considerable emotion, about times when they felt that no heed had been taken of their wishes or needs as people.
Chapter Eight
Discussion of Thesis and Implications for Policy and Practice

8.1 Introduction

In this chapter I present a summary and review of my findings of this ethnographic study undertaken on a children’s ward. The focus of the study was to explore the meaning of dignity on the ward and builds on earlier pilot work (Chapter Four). I shall, in this chapter summarise my key findings and demonstrate where this study has a broader relevance to the care of children and the understanding of dignity at a theoretical and practical level. I discuss the limitations of the study and draw conclusions for policy, practice and research.

8.2 Summary of the study

The aim of this study was to explore and understand the meaning(s) of dignity on a children’s ward, for the children, their parents and the staff. This was in response to the dearth of literature and empirical studies investigating dignity and children and in particular dignity and children in hospital (2.4).

My review of the literature revealed numerous theoretical deconstructions of the concept of dignity from philosophical (2.2.2), theoretical (2.2.3) and applied, medico-nursing perspectives (2.2.4). Recent research has sought to further knowledge of dignity from empirical studies (2.2.5). In particular, studies relating to older people (2.2.5.1) and those in palliative care settings have contributed to an understanding of dignity. These latter studies have relied mainly upon interview and have overlooked those at the other end of the age continuum, children and young people.

In conjunction with my review of literature relating to dignity, I explored research and literature pertaining to the child and childhood. This revealed the construction of the child from a historical (2.3.1), sociological (2.3.2) and political perspective (2.3.3). In keeping with understanding the child as an active agent, the trend in more recent childhood studies has been research with rather than on children (2.3.4; 2.3.5). The use of qualitative methodologies has demonstrated ways of hearing the voices of children.
These approaches were evident in my review of studies exploring the experiences of the child and family in hospital.

I sought an inductive approach to my research and ethnography (3.2.2) enabled me to gain insights into the worlds of the participants and appreciate something of the structures within the hospital environment. Pilot work enabled me to confirm the suitability of an ethnographic approach in conjunction with grounded theory to the study of dignity and the child in hospital.

Data were collected using participant observation and interviews with the children, parents and staff on the ward. I used a grounded theory approach (3.2.3) to my interpretation of the data and to structure my enquiry and analysis. By integrating the two approaches I was able to make a conceptual rendering of the activities of the research participants and construct a theoretical interpretation of dignity of children on the ward. I have drawn from symbolic interactionism (Blumer, 1969; Goffman, 1971; Charmaz, 2006) in my analysis of the data and have sought to demonstrate my process of analysis and decision trail throughout the thesis.

Following the pilot work I remained committed to keeping a flexible and essentially inductive approach to the study. However, I was at this point, able to review and build on the broad aims of the project as it evolved to the next stage. Below I have outlined the revised aims of the study:

- To explore and further the understanding of dignity and the child in hospital.
- To pay attention to the context and the subjective meanings of the participants.
- To evolve or dismiss early indicators and the emergent constructs of the pilot work.
- To identify further themes through progressive analysis concurrent to the data collection.
- Through successive levels of abstraction develop a theoretical explanation or framework in order to clarify the concept of dignity and the child in a way that is meaningful to children and for those who care for them.
- To undertake the research in a non-exploitative, person-centred way.
• To make recommendations for practice such that dignity can best be protected and promoted for children in hospital.

The reality of the environment of the Main Study site characterized by parental presence, limited space and rapid throughput of patients, led me to rethink my methods of engaging children. However, this led me to embrace more fully, the context of the research that proved fundamental to the study and meaning of dignity. By taking an ethnographic approach, I was able to explore the behaviours and the context, rather than relying on what the participants had to say. The perspective of symbolic interactionism assumes that people construct selves, society and reality through interaction and focuses on the dynamic relationship between meanings and actions (Charmaz, 2006). Fundamental to attribution of meaning is the context in which the interaction occurs.

Approaching this research from a Rogerian person-centred approach (5.4.2) demanded that I acknowledge, recognize and engage with the humanness of participants. In this way it was in keeping with upholding the dignity of participants. This approach enabled me to monitor my own feelings and check meanings with participants in the moment. Rogers approach respects the mutuality in relationships and therefore makes it appropriate for research that attempts to facilitate the participation of children, albeit in a somewhat repressive environment.

My relationship was that of researcher of children's experiences and as such I asked questions of the children, parents and staff, in a way that was out of keeping with the non-directive stance of a Rogerian therapist. I also found that in my reflections of events of interviews I drew on other tools of analysis, for example psychoanalytic theory. Nevertheless I was committed to a “way of being” (Rogers, 1980) that honours the personhood of the individual.

My findings reflect the interplay of the two themes that run through the research: the child and dignity. The meaning of the child from the macro societal level through to the micro level of interactions at the bedside is central to the analysis. Equally the translation of dignity at a macro philosophical level is evident in the performance of dignity at the
micro level. The care of the child and the experience of the child is the synthesis of these
two constructs of dignity.

I have interspersed my discussion of my findings with implications for policy and practice
and implications for practice. I have included these suggestions in total as appendix 12.

8.3 The meaning of dignity

From my interviews with children, parents and staff, I extracted different explanations of
dignity. These I clustered into definitions of dignity as what I termed 'intrinsic' and those
of dignity as 'extrinsic'. These two clusters represent a dualism of dignity, that in the
explanations of some participants, coexisted. Thus dignity was understood, broadly, as
having two distinct elements: intrinsic and extrinsic. This dualism was reflected in both
what the staff had to say and what the children and their parents had to say.

This distinction is important because intrinsic dignity is based upon an ideology of all
human beings having equal worth. The inherent and equal value of all people is
fundamental to the United Nations Declaration of Human Rights (1948) and Convention
of the Rights of the Child (1989). Intrinsic dignity applies to the young and the old as well
as the able-bodied and disabled, referred to by Nordenfelt and Edgar (2005) as
Menschenwurde.

Extrinsic dignity is the outward manifestation of dignity in a given social context. The
appreciation of extrinsic dignity was thought, by participants in this study to be acquired.
Some elements of extrinsic dignity are relatively constant between contexts, such as
bodily control and non-exposure. In social environments, such as hospitals, that
challenge social norms of extrinsic dignity, an array of acts, rituals and rules including
the creation of particular roles are constructed. This context specific performance of
dignity practices is used to allay anxiety over the perceived threat of loss of dignity. My
use of symbolic interactionism as a theoretical framework enabled me to attend to the
rules and the way dignity was enacted on the ward. An analysis of the performance
demonstrates the importance of the symbolic meaning of props. Authenticity of
performance and role, is vital if the stated purpose, that of maintaining dignity is to be
felt.
8.4 Acquiring dignity

Staff and parents thought that children developed a gradual awareness of dignity. They drew attention to the way children might not be concerned about bodily exposure (extrinsic dignity) when young, but became acutely sensitive as they grow up. Children acknowledged that this self and body awareness made the experience of being in hospital more difficult as a teenager than when they were younger.

Dignity was thought, by staff and parents, to be learned and modelled through parents. Parents felt that they provided a role model for their children to follow in terms of how they behaved and presented themselves in public. This was particularly true with regard to bodily exposure. Staff were entrusted to continue to promote behaviour deemed appropriate in the parents' absence.

8.4.1 “As if”

Where uncertainty prevailed as to whether a child was aware, or not of what was going on around them and the social connotations of being exposed, the principle to treat children “as if” they had this awareness seemed appropriate (7.7.4). In other words they should be treated in such a way as to not expose them for they might otherwise feel humiliated or degraded, but due to their present condition or age they could not communicate this. It was surprising, to me, that children were not always treated “as if” they had awareness as part of good practice. Where a child was assumed to be unaware, loss of dignity was felt vicariously by the parent.

Implication for practice: If children are unaware of the social norms of promoting and protecting dignity, they should be treated “as if” they had this awareness. It should not be assumed that dignity is not relevant, but be afforded the same attention to privacy and exposure as any other patient.

8.5 Changes in nursing

The sites chosen for the Pilot Study (1999) and the Main Study (2005) were very different in terms of their location and population served. In addition, the site of the Main
Study had recently been updated and redesigned specifically for the care of children, whereas the Pilot site was waiting for redevelopment. Contrasts were also due to passage of time, six years, in which there have been considerable changes in the care of children in hospital and the role of the children's nurse in particular.

Fundamental to a wider change in the way children are cared for when they are ill, has been the increased parental presence and the adoption of family centred care. The National Service Framework for Children (Department of Health, 2003; 2004) upholds the ideal of "care integrated and coordinated around their particular needs, and the needs of the family." This trend is based upon the premise of the beneficial influence of the family in the care of children (Corlett and Twycross, 2006). However, I argue that it has positioned the trained nurse further from the child and intimate care (6.3). The fast throughput of patients and the increase of home care have limited opportunities for nurses to build relationships with the children (6.3.1). Some of the nurses regretted this (6.3.3) and felt that they were left with the "horrible bits" (6.3.2) and an excess of paperwork (6.3.3), leaving less time for establishing relationships with the children. Qualified staff nurses on the ward seemed particularly affected. Arguably past relationships with children were based upon an intimacy forced by the absence of parents. Despite their loss of closeness with the children, staff acknowledged the benefits to the child and the trauma of children otherwise left "alone" on the ward.

Awareness of child abuse (Archard, 1993), and cases of children being harmed by healthcare staff in the media (Royal College of Nursing, 1997), had also affected the way health professionals felt able to communicate affection through touch. As a result some of the children came to associate the touch of nurses with procedures and pain (7.4.1).

Implication for practice: Nurses need preparation to be involved with the procedures undertaken on children. The emotional impact needs to be recognized and strategies offered and learned to manage, rather than deny, emotions.

8.6 Parental presence

Children appreciated the presence of their parents (7.4). Parents of children with special needs felt the need for them to be with their child all the time. There appeared to be a
Resistance by staff to become involved in the care of children with special needs, especially those with special learning or emotional needs. I speculated that staff anticipated an additional burden associated with these children and felt unprepared to address their individual requirements. Warner (2006) suggests that nursing students may have been academically prepared to understand the medical implications of physically and learning disabled children, but may not know how to nurse these children or support their parents. Reticence by staff may also be fuelled by their lack of negotiation skills with 'experienced' parents over what parents are able to do and what they need support with during and after their hospital stay.

Although staff supported the idea, there was an ambivalence at an institutional level about the presence of parents. This was evident from the lack of facilities made available to the parents, some of whom stayed at the bedside of their child for several days (7.5.2.2). Parents were welcomed on the terms of the staff, for example they were discouraged from being with their child during painful procedures (6.4.1.4). The preference of the doctor and those undertaking the procedure took priority, followed by parental choice. The needs of the child did not predominate.

**Implication for practice:** Doctors and nursing require education about the needs of children with a variety of special needs and disabilities, especially those with emotional and learning needs. This includes learning negotiation and interpersonal skills to facilitate good working relationships with the parents and child.

### 8.7 Triad

The presence of the parent precipitated a triadic alliance between the health professional, parent and child. Direct communication between health professional and child was mediated through the parent. This enabled staff to communicate in a way that was easier for the child to understand. Equally the child was able to communicate their opinions and needs through someone they knew and knew them. However, this meant that assumptions could be made and despite any intentions to the contrary, the views of children could be misrepresented. Carter (2002) recognises the notion of "professional ventriloquism" where accounts of a child's pain were reinterpreted through a variety of professional lenses, muting the voices of the children themselves. Parents and children...
appreciated efforts by the staff to talk directly to the child. Parents felt this demonstrated respect for the child (7.5.1). Nevertheless, the relative ease of communicating with the parent could be seductive to the staff as shorthand to communicating with the child (7.5.1.2; 7.5.4). This could lead to the child, being left out, or child and parent being treated as a single unit.

Implication for practice: The voice of the child can become muted in three way communication. Staff need to be aware that this can occur and remind parents where necessary.

8.8 Role of the parent

The constant presence of the mother was often a situation that was out of the ordinary for the child, not only for those of school age. In the thirty years to 2001/2002 the number of three and four year olds attending early education tripled (National Statistics, 2002). In hospital this trend has been reversed with the mothers at the bedside almost constantly undertaking most of the day to day care. For some mothers the line between mothering and nursing was a fine one, and some had become expert in the condition and specialized care of their child. The 'natural' period of caring for such a child was prolonged and the letting go of the parental role as the child matures delayed. The changes in nursing and the associated increased involvement of parents has had repercussions for the role of parents and their relationships with their children when they are ill. The ambivalence associated with this dual role has been highlighted elsewhere. Previous research has found that particularly where parents were involved in performing clinical procedures on their own children, the meaning of parenting was changed (Kirk et al, 2005).

The exploration of the meaning of dignity and the way dignity was performed needed to be considered in this context of a triangular relationship (triad). Parents acted as a constant reminder of the value of their child, more particularly, the value the child had to them. Of this the parents were aware, they were frightened to leave their child for fear that their child may be overlooked. Parents felt obligated to sit by their child, and assume a "vigilant role" (Savage and Callery, 2000) even when this would be a position out of keeping with their norm (7.5.4.2).
Parents reported feeling disempowered, particularly at the beginning of their child’s illness (7.5.2.2). Parents, especially those who were new, “just visiting” the ward wanted to be “good” parents (7.5.3). They did not want to jeopardize the care of their child by alienating the staff. They described having to trust the staff to do their best for their child (7.5.2.2). They were likely to put up with a lack of privacy and less than adequate explanations to keep the medical staff on their side. The label of the “difficult parent” was avoided on the whole (6.4.1.1; 7.5.3.1) and yet some mothers acknowledged their label as an integral part of their fight for their child (7.5.6). Children and parents who had endured long or frequent hospitalizations appreciated honesty and frankness in their dealings with staff (7.5.6.1).

Staff thought that the role of the parent was to be an advocate for their child (6.4.1.1), others appreciated passive parents. Parents felt unsure of their role, others said they were there to protect their child. Some adopted the role of advocate for their child either through choice or in response to anger. The anger of parents fuelled their assertiveness and their feelings resulting from treatments not going to plan or their child not being dealt with in a way that they would have liked, were vented in their discussions with me (7.5.2.3).

With the nursing staff set apart from the child, the close person to the child remained the parent and usually the mother. This closeness was manifested in the way the parents spoke “we” in hospital (7.8.3) and the way they stayed physically close, or often joined on to their child by holding hands, cuddling or sitting next to one another. Parents recognized this connection as an emotional and physical bond as if they shared the experiences of their child viscerally (7.8.3.1).

Implication for practice: Parents are frequently unclear as to their role when in hospital with their child. Staff should offer guidance, supported with written information, and be prepared to negotiate the optimum parental role for the child.

8.9 Construction of the child

Existing power relations between children and adults were compounded in the power exerted by the total environment of the hospital. It was noticeable, having just concluded
some pilot work at a school and nursery, that the children on the ward were not
constructed as social beings (4.4) as they would be in the more 'normal' world of the
child. Children were isolated out on beds almost as a denial of their sociability, their
movements and behaviours were controlled by the physical environment. A playroom
provided activities and entertainment, but children missed their friends. Children and
parents thought that friendships went unacknowledged by staff (7.6.8). They were not
routinely introduced to other children on the ward, nevertheless they displayed an
irrepressible ability to engage with other children. Long term isolation from friends led to
ennui with the lives of the children passing them by in hospital. Similar observations
have been made by Holloway et al (1998), with regard to adult patients in an acute ward.

Fundamental to establishing self identity are the choices one makes over the way we
present ourselves. "A significant element in establishing and sustaining a sense of
self...is how one imagines that one appears to others" (Waksler, 1996). Choices for the
children over presentation of self were very limited on the children's ward. Operating
gowns were disliked by some of the boys who perceived them to be a "dress". Gowns
made them feel "stupid" (7.7.5). Children were taken from the relative privacy of the ward
through public areas of the hospital dressed in hospital clothes and artifacts.
I found that I was influenced by the way children were presented on the ward. It was
difficult for me to hold an alternative construction, that of a well child, to the child I saw
and experienced, before me. In so doing I risked misinterpreting the child (5.3.5) and
misrepresenting them in the data.

The company one keeps is also an important aspect of the presentation of self (Waksler,
1996). Yet choice of company was largely denied in hospital. Adolescents were placed
next to toddlers and friendships dismissed (7.6.8). Not being seen as who you "really
are" created humiliation and embarrassment, emotions that the children related directly
with loss of dignity (7.7.8).

*Implication for practice: There needs to be recognition of the importance for children to
have control over how they present themselves. Alternatives to hospital gowns could be
considered.*
Implication for practice: The sociability of children can be acknowledged by simple measures such as introducing children to those in the bed next to them and placing children of a similar age together.

The developing sexuality of girls was recognized by staff, yet such understanding was absent from the data relating to boys. This may have been a reflection of the gendered bias of the mainly female staff on the ward.

Implication for practice: The embarrassment of boys needs to be acknowledged. They may prefer to be cared for/examined by a male member of staff.

Balen et al (2006) suggest children are constructed as human “becomings” rather than human beings and that their present is sublimated with their future in mind. Invasive treatment for congenital dislocation of hip and correction of bite were examples, from the fieldwork, of interventions with the child’s future in mind, arguably at the expense of their present. This construction contrasts with the way children whose lives are limited are perceived, as for example in the children’s hospice (4.3.1).

Implication for policy and practice: Children with severe and chronic illness can spend a considerable proportion of their lives in hospital, but not be eligible to benefit from the resources of a hospice. The care of these children in District General Hospital facilities needs to be reviewed.

Parents spoke of a child as “my child” in a way that denoted care and relatedness to the child. At the same time “my child” suggests ownership and governance that could deny autonomy. The notion of autonomy had been suggested as a more useful and measurable principle than dignity (Macklin, 2003). The notion of autonomy for babies and very young children, at first seems impossible and inappropriate (Pullman, 1999). Yet autonomy for an infant was readily interpreted by one mother in terms of the freedom to listen and respond to bodily needs such as sleep and hunger when they needed to.

8.9.1 Vulnerability
Parents routinely referred to "my child" in a way that denies agency and also suggests vulnerability. The notion of children as human becomings, "sociologically and biologically unfinished" (Prout, 2000, p. 5) also denies agency and in need of care and protection. Christensen (2000) discusses the notion of vulnerability as it relates to children. She highlights the way children are constructed as vulnerable. Children, Christensen argues, especially sick children, are viewed as needing adult care and intervention. By positioning the child as dependent and passive can paradoxically, render their own understandings of themselves and their bodily experiences as unimportant. The findings suggest that babies were thought to be particularly vulnerable, a reflection of their restricted physical mobility and function. Babies were at the mercy of those who could pick them up, perform procedures on them (7.9.6), clean them and clothe them. They were limited in their ability to communicate, or at least be understood and listened to (7.5.1). Children with disabilities or special needs were also vulnerable. Their care was handed over to their parent, but this could have the effect of further isolating these families.

*Implication for practice: Staff need to become more aware of their own behaviours in exacerbating the vulnerability of babies and those with special needs, through education and reflective practice.*

The findings also demonstrate that both staff (6.4.1.3; 7.5.2.2) and parents held back from voicing any disquiet they may have about the treatment of children. Both parents (6.4.1.4) and staff thought that at times it was helpful to minimise the pain and experience of their child, although this could be at the expense of understanding the child's subjective experiencing of events.

8.10 Control

Lansdown (1994) suggests that the dominating feature of childhood is that of powerlessness and lack of control over what happens to them. Certainly children have a different experience from adults of control over their lives and their bodies. In her discussion of the "hard times of childhood", Waksler (1991) describes the way children are denied control over their own lives. She breaks this down further into: lack of control over the physical world, the world of emotions and the moral world. The lack of control in
the physical world includes the denial of control children experience over their own bodies, such as others deal with their bodies against their will or without their permission. In addition they are denied control over activities and how they conduct themselves, their appearance and thus the presentation of self, their relations with others and the way they may choose to cope with inadequacies or inabilities. All these were shown to be pertinent in the health care setting.

Children were constructed in such as way as to control their activities (isolated on beds) and denied their sociability. Their choices and presentation of self were limited and overpowered by hospital rules and routine. Constant surveillance, on the premise of a need for observation of a sick child, denied privacy to the child and parents. Families were required to live their lives under the scrutiny of "legitimate" witnesses such as the staff, but also other parents and children. Control of self, one's body, emotions and autonomy are fundamental to notions of dignity (2.2.4). In hospital, control was imposed from the point of entry to the ward, both implicitly, for example through restrictions imposed on me as researcher (5.3.2) and explicitly through locked doors and control of privileged access (5.2.1). The time of the children and their families was also largely controlled by the hospital routines and subordinated by demands of the schedules of the staff (5.2.12). Staff complained of being too busy and not having enough time and children complained of ennui and their lives outside of hospital passing them by (Holloway, et al, 1998).

**Implication for policy and practice:** Respect for children in their parents includes staff valuing their time. Children and their parents should be given accurate information on waiting times and appointments and procedures scheduled with their agreement.

Control was sought by the parents who may have struggled to interpret and manage the child's illness at home. The seeking of "medical judgment" has been described as the seeking of the "management of uncertainty" (Lupton, 1996, p.162). Parents presented with their child, asking for expert help, but admission was also dependent upon the legitimization of illness (7.8.4). Children were often 'held' in Ambulatory Care on entry to the ward. A liminal period followed whereby the staff observed, examined, measured, tested and investigated the child's body for anomaly and deviation from the norm. Liminality describes a period of transition when the child is transferred from the control of
the parent and incorporated into the control of the professional on the legitimization of illness. Admission under the responsibility of a named consultant infers the transfer of the child’s ownership (Shields, 2003).

Implication for practice: The uncertainty and anxieties of parents, including their need for visual and auditory privacy needs to be recognized and addressed particularly in the Ambulatory Care, or pre-admission area.

8.11 Strangeness

Strangeness (5.3.1) was a compelling and controlling feature of the ward environment for myself, as researcher, and the children and their families. This part shared experience of alienation, for me as researcher, contributed to data (3.4.2) and insights. Children and their families craved normality in an environment that was very alien. From arrival on the ward, they were required to interpret the subculture of the hospital with social rules at odds with those outside (Warren, et al, 2000). Central to rules of the ward were those that concerned dignity.

Short stay children managed strangeness by ‘just visiting,’ in which they suspended their normal lives for the duration of their admission. Children who were in for longer were obliged to ‘live in’ hospital and had to adapt their ways of living to the hospital. Despite recognition by the staff for the need for normality in their patients’ lives, opportunities to hold on to normality were limited, especially in the open bays. For those who were ‘visiting’ the ward, activities, the television and the play room kept them occupied. Those ‘living in’ experienced a sense of ennui and disconnection from peers.

Parents and children spoke of striving for normality in terms of their every day lives, yet few possessions, clothes and reminders of home, including friends were able to be brought in. Such personal effects maintain one’s sense of self and self in relation to others. The way one presents one’s self is important in conveying self to others, and dignity is integral to sense of self (7.7.5.8). The body mediates the relationship between self identity and social identity (Shilling, 2003). Children and their parents sought normality in their physical bodies, but where children and their families yearned for normality, the staff were on the look out for strange anomalies.
Patients are able, and willing to be controlled in hospital, on the basis of expert knowledge of the staff who worked there. In the same way children are able to be controlled by adults because adults are assumed to know better. Staff used their position as experts to define the best interests of the children (6.9.2; 7.9.9). Often best interests were determined upon the perceived future benefits of a particular choice of action to the child. This could be at the expense of the child’s experience in the present. Carnevale (1997) in his ethnographic research in a Paediatric Intensive Care Unit coins the uncomfortable term, “aggressive care.”

In order to carry out procedures in the “best interests” of the child, the child sometimes needed to be restrained. It was commonly espoused on the ward that it was this “being held down” that the children objected to (6.9.1.2). I argue that this innocuous sounding assertion that the child did not like being held down was, at least in part, a denial of a child’s pain and that it was the procedure that was causing him or her pain. It was as if this was an assumption to contain the anxiety provoked by the prospect of hurting a child.

Implication for practice: Staff should be encouraged to reflect upon and challenge the notion of best interest and “holding down” to ensure that the needs of the child take precedence.

Implication for policy and practice: A commitment to the prevention and alleviation of pain in all children including infants should be at the heart of policy and practice. This includes the use of current evidence based guidelines on the use of analgesia by all staff.

8.12 The Body

The body became the stage on which the performance of dignity, in the context of the hospital ward was enacted. The bodies of the children have different historical, biological and social meanings (Prout, 2000). On the one hand the body of the child is, and was, a biological construct constructed, scrutinised and reconstructed under the clinical gaze
(Foucault, 1973). On the other hand the embodied child, the child in his or her body became a focus of my research.

Admission to the ward was dependent upon the legitimization of a medical anomaly (7.8.4). I have described the legitimization of illness as a liminal process during which the parent hands over the child to the control of the medical staff (7.8.4). Equally, discharge was decided upon objective measures of wellness rather than the child’s subjective experience. Children were measured against the norm (7.6.4). Persistent failure to meet the “gold standard” of normality could result in stigma, a spoiled identity (Goffman, 1963).

There was a curious ambiguity about where the body’s boundaries ended. Naso-gastric tubes and drains had an uncertain meaning as neither a part of, or apart from the child’s body. They penetrated the body barrier of the skin and allowed the outflow of bodily fluids, externalizing the workings and dirt of the body. Indicators that could be considered as “stigma markers” (Goffman, 1963). Staff and parents would handle these drains in a way that seemed to cause embarrassment to the child (6.8.1).

*Implication for practice: Staff and parents should treat naso-gastric tubes and drains as if part of the child’s body liable to cause embarrassment and handle them discretely after first asking the child.*

The child’s body as a biological construction was simultaneously a social and socially constructed body. Central to an understanding of dignity and the child, is the embodiment of the child. The body is the vehicle in which the child navigates his or her social world. Meanings are attributed to the child’s body. These actions and reactions of others are given meaning and these meanings are internalized and help to reinforce a self identity (Williams and Bendelow, 1996).

Staff managed the bodies of children throughout their hospital stay: covering exposed bodies, observing, measuring and breaching body boundaries. Staff also assumed governance of pain, sometimes causing, sometimes interpreting and sometimes alleviating pain. I argue that children, and in particular their bodies were overly managed
by the staff (7.8). I speculate that this was a reflection of a time when staff themselves may feel over managed.

Children became habituated to the repeated examinations and their surrender to bodily exposures was capitalised by staff. I argue that this attitude was encouraged (groomed) by staff for future use as medical exhibits and teaching aids. Featherstone, et al (2005, p.551) in their discussion of dysmorphology and the “spectacle of the clinic”, argue that the “‘gaze’ of the clinician” and the “clinicians warrant of personal knowledge” enable doctors to exert their influence. This process defined children as a medical curiosity in denial of them as children.

Implication for policy and practice: Policies relating to the use of children in teaching sessions or examinations should be reviewed. Willingness to take part may be dependent upon desensitization (habitation) to bodily exposures.

8.13 Witness

The lives of children and their families were very much ‘on show’ in the hospital ward particularly in the Pilot Study (4.2.8). In both sites however, for the children and their families there was no distinction between the public and the private domains. Thus the most intensely private features of their lives were brought under the scrutiny not only of nurses and doctors, but also other families. This was in spite of the attempts of the staff to offer and create “private” areas for patients (6.2.1).

Implication for practice: Parents and children should be seen away from public areas wherever possible. It is rarely possible to predict the course of an interview or the reaction and sensitivities of the child/parent.

Parents on the ward were acutely sensitive to others and discussions about their child taking place in the open theatre of the ward (7.10.2). The “others” were witnesses to

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9 The power of the witness on the potential for humiliation of another is succinctly expressed by John Merrick (Montague, 1971) otherwise known as the “Elephant Man” who asked: “When I am next moved can I go to a blind asylum or to a lighthouse?” - a sanctuary where he would be free from the eyes of others.
events as they unfolded. On occasion these witnesses were reviled because of their power to precipitate strong negative feelings. Willing or not (7.10.5) they were the arbiters of events. The witnesses themselves may also experience emotions in a vicarious way, but almost as if they were practising such emotions in the safety of knowing that it was not actually happening to them.

The effect of a witness on the experience of dignity demonstrates the transactional nature of dignity. Dignity is experienced in relation to another and it is the manner of 'the other' and the meanings attributed their reactions that have implications for whether dignity is maintained or lost.

In contrast to Wainwright (1994), Mairis (1994) and Shotton and Seedhouse (1998), Haddock (1996) places greater importance on the relationship between observer and observed. She does not mention witnesses, but alludes to the qualities required in the nurse and the transactional nature of the nurse/patient relationship in the preservation of dignity. Her stance is reminiscent of the humanist perspective of the psychotherapist Carl Rogers (1957) who defines the core conditions necessary for a therapeutic relationship as: empathy, congruence, and unconditional positive regard.

I argue here that the qualities of the observer, as perceived by the patient, and their relationship are key to the effect that witnessing has on an event and whether a loss of dignity results. I suggest that it is the transactional nature of the nurse-patient relationship that is all important in allowing the patient to feel dignified. It is this relationship that has the potential to acknowledge the strength and inherent dignity of the individual, perhaps in circumstances that would otherwise be degrading or humiliating. I was curious how the meaning and sense of dignity for children was promoted and protected by the actions of the staff. I have described the dualism of dignity as something that is intrinsic and something that is socially proscribed and external (extrinsic), now I will proceed to describe how the meaning of intrinsic value is articulated by attending to the socially defined and context dependent criteria of extrinsic dignity.

8.14 The performance of dignity
Erving Goffman, the Canadian sociologist employed a model of the theatre and performance to examine and explain social life (1971). He focused upon the meaning of interactions between players. Central to the core of this ethnography was the performance of dignity. While I developed a better understanding of the meaning dignity had for participants I was able to explore how dignity was ‘done’, how these meanings translated into actions and actions into meanings. The social rules and rituals of dignity have to do primarily with the process by which we “do” dignity and, in turn, honour the worth of the recipient in a socially constructed, culturally appropriate way. This has evolved, in the context of the hospital ward, into a complex collection of behaviours centred upon some basic premises, in particular promotion of dignity is dependent upon prevention of exposure of the body and loss of emotional control.

The staff, the nurses in particular, invoked a stylized performance of dignity in which they sought to demonstrate a regard for the individual dignity of a patient through particular ritualized behaviours. Dignity was performed using "props" with actual and symbolic meaning, for example curtains (7.11.1.1). Rules determined the way procedures were carried out, with some rules having priority (7.11.3). Most of these behaviours were associated with the way the body was managed in a dignified way. Performance also included talking directly with the child and family, chatting with them to suggest interest in them as people.

The acknowledgement of the intrinsic value and dignity of an individual, required complex behaviors and procedures that focused on their extrinsic dignity. Staff performed dignity using props and symbolism at a time and in an environment where dignity was threatened. This was often done in ritualized ways, I argue, as a performance. Behaviours such as drawing the curtains, even if the curtains are not sound proof and provide limited privacy, have acquired a socially accepted meaning. These behaviours were appreciated by parents.

The manner of the performance was important. Child patients and their parents liked the staff to know what to do, to handle difficult, awkward or embarrassing situations. Understanding the performance of the staff could be more problematic as children did not always appreciate the social symbolism of a behaviour or an artifact. The reluctance...
to wear a surgical gown, as described by three of the boys was an example of this (7.7.5).

There was a tension between performance of dignity and the meaning of dignity. There could be a preoccupation with stylized, socially constructed behaviours and rules. Staff could be distracted by the actions and behaviours related to the management of bodies as opposed to attending to and attempting to uphold the meaning of dignity as a fundamental value of all humans, however young. Competing agendas, such as the pressures of work and the vulnerability of children, compounded the risk of obscuring the essence of dignity for the children and parents in their care.

The performance and learned ritual of dignity had another purpose in the emotionally charged “vibe” of the children’s ward. I argue that performance acquitted the staff member from having to revisit the meaning of dignity for the individual on each separate occasion, a sort of “short cut. Performance and ritual also helped manage the tensions and ambiguities that were manifest in promoting and preserving dignity in the ward environment. However, performance could also serve to distance a staff member and in turn hold power over the child and family.

The meaning of dignity as understood by staff could sometimes be lost in translation in the operationalisation of dignity. Promoting dignity was reduced down to pulling curtains, while the essence of dignity evaporated. Rather than staff always understanding the symbolic meaning of these behaviours they mistook dignity to be the pulling of curtains and the covering of bodies.

*Implications for policy and practice: An understanding and debate of dignity needs to assume a central position in the education of medical, nursing and other hospital staff.*

8.15 “Dignity matters” – the emotion work of participants

Dignity was important because of the emotions the loss, or threatened loss, of dignity invoked. Where an individual, such as a child, was unaware of dignity as a manifestation of social norms then, it seemed, emotions were felt and expressed vicariously by the
parent. This was also apparent in the outrage expressed following the perceived degradation of their child.

Nevertheless, the emotional reaction of children and their parents could be mediated through the performance of the staff and how they worked on their own emotions in order to induce or suppress feelings in others. An effective performance of dignity therefore was not just about operationalising its components, but by the way dignity was enacted. Hochschild (1983) in describing the work of flight attendants calls this “emotional labour” and it is a concept that has been applied to the work of nurses (Smith, 1992; James, 1989; Staden, 1998, Bolton, 2000; 6.12).

Lawler (1991) describes how managing emotions is all part of the professionalism of the nurse. The manner in which staff performed dignity was important in how they were perceived as credible. Integral to performance of a staff member was the management of their emotions.

Nursing staff spoke about their role in children’s nursing. They described ways in which they related to the children, that I categorised in four ways: tuning in, moderating, detaching and integrating. Staff used themselves to understand others. They also managed their emotions in such a way as to induce or suppress emotions in the children and their parents. Lawler (1991, p.146) suggests that when performing a procedure, nurses work to contain the indignity felt by a patient:

“Nurses manage their own responses by their lack of embarrassment (affect) nurses redefine situations for patients so that the patient need not feel embarrassed.”

So nurses may be able to work in a way that has least negative affect on the dignity of the patient. Wainwright (1994) in his discussion of dignity and the intimate aspects of care, notes that for ridicule to take place a necessary element is the “presence of observers bearing a certain attitude” (p.50). In the same way that staff were able to maintain a sense of dignity, they also had the power to humiliate (7.5.5). Detaching was a way of not engaging with the experience of the child and family. Assumptions and learned explanations enabled staff to detach from the subjective realities of their patients.
There was evidence of emotion work being undertaken by parents (7.12.2) and children (7.12.3). There was a curious covert denial of all the unusual and strange sights by patients and their relatives in hospital, who kept their overt reactions to the minimum (4.2.4). Davies (2004) describes this "switching off" attitude of one patient to another in order to preserve their dignity. It was as if they were abdicating their role as witness for the sake of the other.

8.16 Being Human

Children and parents craved recognition of their shared humanness and despised objectification. It was apparent from the findings that children and their parents craved being acknowledged (7.13.1). Parents spoke with great emotion of how they had felt their child had been objectified (7.13.4) and not recognized as an individual person. They wanted to feel as if they mattered and were important and engaged actively in their care. They wanted to be listened to and their opinions respected. Children wanted to be spoken to directly and not over (7.13.1). Parents could act as advocate for their child, but more than this their presence reminded staff of the value and humaness of their child.

I argue that the fact that dignity could be denied for children and children acted upon in a way that seemed to deny their very humanness is not only a detachment from the subjective experience of the child, but also a reflection of a child's position in society. It is a position relative to an adult.
9.1 Introduction

In this chapter I discuss some of the limitations of this study and I make suggestions for further research. Finally, I draw this account of my research to an end with concluding remarks to the thesis.

9.2 Limitations of the study

9.2.1 Ideologically founded research in a real life situation.

Prior to embarking upon the fieldwork I had been inspired by the approaches to childhood research that placed the child at the centre. Not only were children active agents in the research, but the methods used to co-construct and analyse the data were child oriented. I struggled to achieve this ideal in the hospital. The power differentials between adult and child and staff and patient were already set and the agenda of the medical team was far more credible than my own.

I had wanted to engage informally with children through activities and play. However, the children were not active on the ward. In order to talk with the children, I had to approach them more formally at their bedside. This had implications for the data I collected. In order to offset the limitations of the direct approach I took greater heed of the context. Rather than the dignity of a child, the research became a study of dignity and the child in the context of the hospital ward. Ethnography was an appropriate methodological approach for such a perspective.

9.2.2 Researcher participant relationships

There were times when I felt uncomfortable with a position of power bestowed upon me by the virtue of being an adult. This was ameliorated to some degree by the presence of a parent at the interviews. Hence the triadic relationship I observed with families and staff, I found myself mirroring in my interviews. Together, parent and child co-
constructed the story of dignity in the same way they co-constructed the story of the child's illness.

9.2.3 Researcher as witness

If the presence of a witness is a key threat to the dignity of an individual, this presented a real dilemma when contemplating the use of observational methods to research the phenomenon. This is especially true where the subject of the proposed enquiry is the child. I tried to be sensitive to the feelings of inquiry, so deeply felt by children and their parents, and not abuse my access. The words of Alderson are cautionary to would be "ethical" researchers and so pertinent to the study of dignity:

"...morality seems to be reduced to manners, to an etiquette of being seen to do the correct thing, rather than of wanting and trying to do so" (Alderson, 2001, p.206).

9.2.4 Use of negative scenarios

In determining the meaning of dignity I, like the participants in this study, found it easier to identify what dignity was not. My use of negative cases should not be taken as a slight on the care provided by the staff on the ward. This research was not about measuring levels of dignity on the ward, but rather a "general wonderment" (Cutliffe, 2005) about the meaning of dignity and the child in hospital. In this way I tried not to force data into preconceived ideas about what dignity was or was not but rather I tried to let themes from the data emerge. Nevertheless, the study does highlight areas of concern to be addressed that emanate from the subjective experiences of the children, parents and staff.

9.2.5 Transitory childhoods

The nature of life is that one is always in transition. The particular temporality of childhood is identified by Mayall (1998) who describes the child as people now and people in the future, this could render them more vulnerable in decisions about care. It also created challenges for research. I am aware that I was, at times critical of images of the children created from a clinical gaze, but I had to bear in mind that the child I saw
before me was a snapshot in time and that any construction I made during the course of my research was just that, a snapshot.

9.3 Further research

In this section I highlight four areas from the thesis that warrant further inquiry. The first is practically based, the others are more theoretical.

- Cannula were sited and irregularly maintained. They were removed just prior to discharge. Cannulae were disabling and sometimes painful for children and should only be used where they are needed and maintained to ensure viability. Regular audits of cannula siting and use could alleviate the stress caused.

- Comparative studies of dignity cross the age continuum could highlight shared prejudices and vulnerabilities and develop understanding of dignity. Established practices and theoretical developments could be assessed for appropriateness and incorporated into 'new' areas.

- An ethnographic study of life limited children would further enhance understanding of dignity and children.

- Research into the ways sexuality in children and young people is understood and respected in hospital.

9.4 Concluding remarks to the thesis: Dignity and the child in hospital.

Children are small, they have quiet transitory voices that, like dust, can be swept away. The very absence of children in the literature pertaining to dignity, should alert us to the possibility that dignity and the child, until now, has indeed been brushed aside. This thesis describes an original piece of research exploring the meaning of dignity for the child in hospital. In it I have described my ethnographic approach to the study and demonstrated how I have illuminated themes, grounded in the data that explain something the nature of dignity in this context. Attention to the “strange” aspects of the
research setting allowed me to question the meanings of behaviours and the roles of participants.

The management of emotions was central to the portrayal of dignity. By putting these behaviours under the "spotlight," I was able to examine the micro actions that constituted the performance of dignity. Childrens' bodies provided the platform for these enactments. The boundaries of children's bodies were at times uncertain, being invaded by cannulae, nasogastric tubes and drains. The clinical gaze of the child as object has been challenged in my attempt to explore the experiences of the subjective embodied child. Qualitative interview enabled me to hear something of these subjective experiences of the children, staff and parents.

I have proposed a dualism of dignity where the meaning of intrinsic dignity is articulated through the performance of socially proscribed acts of extrinsic dignity. Reference to the wider societal meaning of the child and power relations within and outside the hospital ward, threw another filter over my lens. That dignity could be denied and children acted upon in a way that denied their very humanness, is a reflection, both of the ability of hospital staff to detach from the lived embodied experience of the child, as it is of the relative position of the child in society.
Dignity and the Child in Hospital

Appendices

1. Information sheet for parents and their children
2. Consent forms
3. Interview schedule
4. Ethics approval letter (Surrey Local Research Ethics Committee)
5. Ethics approval letter (University of Surrey)
6. Refined protocol to children's hospice
7. Data sheet for staff
8. Data sheet for child participants
9. Extract from interview with 1MN
10. Extract from interview with 7FN
11. Extract from interview with mcm4052 and cm4052
12. Implications for policy and practice

Bibliography
Information sheet for staff

Research Project: Dignity and the Child in Hospital

About the researcher.
My name is Paula Reed and I am Registered Nurse studying for a research degree at the University of Surrey.

What is the purpose of the study?
This study is designed to explore and understand the nature of dignity in the child in hospital. I would like to capture the child’s perspective and exploring how dignity is experienced and expressed by the child.

Have you done any pilot work?
I have undertaken a similar study in a children’s ward in London, as well as some observations in a nursery, and school.

What will you be doing?
I will be observing and taking notes. I may use a voice recorder if participants like it. I may be playing or drawing with children, or just talking with the children and their carers. I would also like to talk to the staff.

The ward is very busy, will you get in the way?
I hope not! I am very willing to help make beds, give out meals etc. Indeed, this was something I did during the previous pilot study. Please feel free to ask me to leave if things get too hectic.

Will you be visiting anywhere else in the hospital?
I will also be visiting A&E and Out Patients.

Which children will be involved?
All the children on the ward, babies through to adolescents, will be eligible for the study. I have prepared an Information Sheet, similar to this for parents, carers and children. I will not be including children in the study unless I have their consent (where able) and that of the parent/carer.

What about if the nurses/doctors think that a child is too sick to take part?
When I arrive each day, I will report to the nurse in charge and check to see if any of the children are not suitable to approach that day.

What about confidentiality?
Any notes that I make will be kept confidential and there will be no identification of individuals.
When will you start on the ward?
I am hoping to start on the ward at the beginning of March.

How long will the research take?
The study will run for approximately eighteen months with most of the observations and interviews on Hascombe Ward completed in the first six months.

When will we find out about what the study shows?
You are most welcome to ask me about the research at any time. I will arrange to present my findings to date in May in a more formal way.

Paula Reed
European Institute of Health and Medical Sciences
University of Surrey
Guildford
Re: Research into the dignity of the child in hospital

- Consent Forms
  - A white - Older child
  - B white - Younger child
  - Blue - Parental assent
  - Lime green – Parent consent to interview
  - Yellow – Staff
Consent Form

- I have read the attached information sheet in which I have been asked to participate in the research. I have been given a copy of the information sheet to keep for future reference.

- The researcher has explained to me, ........................................, the purpose of the research and I believe that I understand what is being proposed.

- I understand that the information collected during the course of the research will remain confidential. Only the researcher and her supervisor will have access to these notes.

- I have had the opportunity to discuss the details with the researcher and to ask questions.

- I have received satisfactory answers to all my questions.

- I hereby fully and freely consent to taking part in this study.

- I understand that I am free to withdraw my without giving a reason for withdrawing and without affecting my care in any way.

Name of participating child .......................................................... Date
Date of birth ..................................................................................

Name of parent/guardian of participating child..........................................................
Relationship to child ..........................................................................
Signature .......................................................... Date

As the researcher responsible for this investigation I can confirm that I have explained the participating child named above, the nature and the purpose of the research to be undertaken.

Signature of researcher.......................................................... Date
Appendix 2: Consent Forms

Centre Number: 
Child Patient identification number for this trial: 
Version 6, 06/02/03

Title: Dignity and the child in hospital

Name of Researcher: Paula Reed

University of Surrey
Guildford
Surrey GU2 7XH, UK
Telephone +44 (0)1483 300800
Facsimile +44 (0)1483 300803

European Institute of Health & Medical Sciences
University Campus
Duke of Kent Building
Stag Hill
Guildford
Surrey GU2 7TE
Telephone +44 (0)1483 686700
Facsimile +44 (0)1483 686701

Consent Form

- Paula Reed has told me why she is on the ward.
- I know that Paula Reed wants to come to the ward and see what happens on a children’s ward.
- I know that Paula wants to talk to me about being in hospital.
- I know that Paula would like to play with me and do drawings.
- I know that Paula will be writing down some of the things she sees and some of the things I say.
- Paula will keep what she writes down as secret so as no one will know who she is writing about.
- I would like to talk and play with Paula.
- I know that talking and playing with Paula will make no difference to my treatment.
- If I don’t want Paula to talk and play with me anymore, I can tell her to go away and it will make no difference to the way I am looked after by the nurses and doctors.
- Paula has given me this piece of paper to keep, she has a copy of it and so do the doctors.

My name _______________________________ Date..............

Name of parent/guardian______________________________ Date..............

I, Paula Reed have told ____________________________ about why I am here on the ward and explained what I will be doing.

Signature of researcher______________ ______________________ Date..............
Dignity and the Child in Hospital
Appendix 2: Consent Forms

Centre Number:
Child Patient identification number for this trial:
Version 6, 06/02/03

Title: Dignity and the child in hospital
Name of Researcher: Paula Reed

Consent Form

- I have read the attached information sheet in which I have been asked to allow .................to participate in the research. I have been given a copy of the information sheet to keep for future reference.

- The researcher has explained to me, .............................................., the purpose of the research and I believe that I understand what is being proposed.

- I understand that the information collected during the course of the research will remain confidential. Only the researcher and her supervisor will have access to these notes.

- I have had the opportunity to discuss the details with the researcher and to ask questions.

- I have received satisfactory answers to all my questions and those of my child.

- I hereby fully and freely consent to my child taking part in this study.

- I understand that I am free to withdraw my child without giving a reason for withdrawing and without affecting the care of my child in any way.

- I understand that .........................can withdraw at any time without giving a reason for withdrawing and without affecting his/her care in any way.

Name of participating child
Date of birth

Name of parent/guardian of participating child
Relationship to child
Signature
Date

As the researcher responsible for this investigation I can confirm that I have explained to the parent/guardian of the participating child named above, the nature and the purpose of the research to be undertaken.

Signature of researcher
Date
Title: Dignity and the child in hospital
Name of Researcher: Paula Reed

Consent Form

I have read the attached information sheet in which I have been asked to participate in the research. I have been given a copy of the information sheet to keep for future reference.

The researcher has explained to me, ........................................, the purpose of the research and I believe that I understand what is being proposed.

I understand that the information collected during the course of the research will remain confidential. Only the researcher and her supervisor will have access to these notes.

I have had the opportunity to discuss the details with the researcher and to ask questions.

I have received satisfactory answers to all my questions.

I hereby fully and freely consent to taking part in this study.

I understand that I am free to withdraw without giving a reason for withdrawing at any time and this will not affect the care or treatment of my child in any way.

Signature of participating parent ..................................................Date.............

As the researcher responsible for this investigation I can confirm that I have explained to member of staff named above, the nature and the purpose of the research to be undertaken.

Signature of researcher.......................... ........................................Date.............
Consent Form

- I have read the attached information sheet in which I have been asked to participate in the research. I have been given a copy of the information sheet to keep for future reference.

- The researcher has explained to me, ................................., the purpose of the research and I believe that I understand what is being proposed.

- I understand that the information collected during the course of the research will remain confidential. Only the researcher and her supervisor will have access to these notes.

- I have had the opportunity to discuss the details with the researcher and to ask questions.

- I have received satisfactory answers to all my questions.

- I hereby fully and freely consent to taking part in this study.

- I understand that I am free to withdraw without giving a reason for withdrawing at any time.

Name of participating staff member ...........................................Date...............  
Staff grade ..............................................................................  

As the researcher responsible for this investigation I can confirm that I have explained to member of staff named above, the nature and the purpose of the research to be undertaken.

Signature of researcher.................. .........................................Date...............
This document outlines the framework for interviews for

1. staff,
2. parents, and
3. children.

Written consent will be obtained as per protocol prior to interviews.

The purpose of the interviews with the adults is to explore the ways in which the concept of dignity is understood by different people, from their differing perspectives as staff or parent. I want to keep these discussions as open as possible to restrict my influence on the participants. Data from the unstructured discussions of the pilot suggests that some of the following areas are likely to come up: how dignity differs, if it does, between adults and children and how it can be promoted for children in hospital. What the interviewees think is difficult for children in hospital and what threatens their dignity. Whether they have any of their own memories of lack of dignity, humiliation, embarrassment, the impact of control or restricted choice when they were children.
Framework for Qualitative Interviews

1. **Staff members.**

Ward staff will be interviewed to explore their understanding of dignity in relation to children. The interviews will have an unstructured format, but will have a common "beginning frame"

**Staff members – Beginning Frame**

As you know my name is Paula Reed and I am a PhD student at the University of Surrey. I am very interested in the dignity of children particularly when they are in hospital. I am very keen to hear what the staff on this ward have to say, and that is why I have asked you to be interviewed.

I would like to tape this interview, the tape will remain confidential to me. Only Professor Pam Smith and Professor Geoff Hunt will be able to listen to this tape after I have removed any identifiers such as your name from it. The tape will be kept in a locked filing cabinet. Is that O.K? Do you have any questions before we begin? Please let me know if you would like me to stop the tape at any time.

- Can you tell me what your job title is?
- How long have you been working on this ward?
- Can you tell me a bit about your previous work experience?
- Do you have children of your own?

The following section will be more unstructured but will include the following lines of inquiry:

As you know, my research is looking at dignity and the child, particularly the child in hospital.

- What do you understand by the term dignity?
- What comes to your mind when you think about dignity and children?
- Do you think dignity changes as you grow up?
- In what ways?
- What things are really important for children when they are in hospital?
- Is it always possible to provide the things that are important for the dignity of a child in hospital?
- How do you think dignity can be promoted for children?
- What about the babies?
- What role do you think the parents have in promoting the dignity of their child?
- What role do you think the staff have in promoting the dignity of the children?
- What about the children themselves, do you think they are able to play a part in protecting their own dignity?

Thank you for your time. I have finished my questions. Is there anything you would like to ask me?
Appendix 3: Framework for Qualitative Interviews.

Framework for Qualitative Interviews

2. Parents/guardians

Parents/guardians will be interviewed to explore their understanding of dignity in relation to children generally and their child in particular. As with the staff members, the interviews will have an unstructured format, but will have a common “beginning frame”

Parents/legal guardians – Beginning Frame

As you know my name is Paula Reed and I am a PhD student at the University of Surrey. I am very interested in the dignity of children particularly when they are in hospital. I am very keen to hear what the parents and carers of the children on this ward have to say, and that is why I have asked you to be interviewed.

I would like to tape this interview, the tape will remain confidential to me. Only Professor Pam Smith and Professor Geoff Hunt will be able to listen to this tape after I have removed any identifiers, such as your name and that of your child from it. The tape will be kept in a locked filing cabinet. Is that O.K? Do you have any questions before we begin? Please let me know if you would like me to stop the tape at any time.

- Can you tell me how long you have been on the ward
- How old is your child?
- Why did ..............(child's name) have to come into hospital?
- Is this the first time, or have there been other times?
- Do you have other children?

The following section will be more unstructured but will include the following lines of inquiry:

As I have explained, my research is looking at dignity and the child, particularly the child in hospital.

- What do you understand by the term dignity?
- What comes to your mind when you think about dignity and children?
- Do you think dignity changes as you grow up?
- In what ways?
- What things are really important for children when they are in hospital?
- Is it always possible to provide the things that are important for the dignity of a child in hospital?
- How do you think dignity can be promoted for children?
- What about the babies?
- What role do you think the parents have in promoting the dignity of their child?
- What role do you think the staff have in promoting the dignity of the children?
- Can children play a part in making sure their own dignity is protected?

Thank you for your time. I have finished my questions. Is there anything you would like to ask me?
3. Interviews with the children.

The interviews with the children will be even less structured and drawing or play may be used to help the discussions along. However, the interviews will start with a beginning frame similar to those of the adults. The parents will invariably be there, as they will be encouraged to stay with the children to overcome the reluctance the children may have about being with me. However, the children will be encouraged to speak for his/her self either directly or with the use of drawing or play materials.

Children – beginning frame.

The language used will be adjusted and timed according to the child’s level of understanding and ability to respond.

As you know my name is Paula Reed and I am a student at the University of Surrey. I am very interested in the dignity of children particularly when they are in hospital. That means that I am interested in what makes you feel good while you’re in hospital and the sorts of things that make you feel not so good – the things you like and the things you don’t like so much. I am very keen to hear what the children on the ward have to say, and that is why I have asked you if it would be O.K. to talk with me. You can do some drawing if you like to show me the sorts of things you are talking about.

I would like to tape this interview, the tape will remain private to me. Only two people who help me with this work, Professor Pam Smith and Professor Geoff Hunt will be able to listen to this tape. But that will only be after I have removed your name form it. Then I’ll put the tape in a locked filing cabinet. Is that O.K? Do you have any questions before we begin? Please let me know if you would like me to stop the tape at any time.

- Can you tell me how long you have been on the ward
- How old are you?
- Why did you have to come into hospital?
- Is this the first time, or have there been other times?
- Do you have any brothers and sisters?

The following section will be more unstructured but will include the following lines of inquiry:

Many of the children will not have much to say about dignity per se so the questions will be based on what they think about some of the things that happen to them, particularly on the ward and how that makes them feel. What things they like about hospital and what they don’t like. Ward activities and personal care may form the basis of the interview. Where drawings facilitate the discussions, their meaning will be attributed by the child in a patient centred approach rather than analysed by me as the researcher. The drawing will remain the property of the child. I ask, if they do not mind, to photocopy their drawing as a record of our talk.
9 April 2003

Ms Paula Reed
Anchor Down
10 Shepherds Hill
Haslemere
GU27 2NF

Dear Ms Reed

Dignity and the child in hospital

I am pleased to be able to inform you that at its meeting held on 8 April 2003 the Ethics Committee approved the above study.

The Committee’s decision was based on its review of the following documents:

(i) The South West Surrey LREC Application Form which you signed on 14 February 2003.
(iv) Consent Forms for the Older Child, Younger Child, Parental Assent, Parent Consent to Interview and Staff all version 6 dated 6 February 2003.
(v) Letters to Consultant Paediatricians at the Royal Surrey County Hospital and the GP.

The Committee’s approval is subject to the following conditions:

(i) No changes should be made to the documents listed above or the procedures set out in them without prior written approval of the Committee.
(ii) The project must be started within three years of the date on which the Committee approved the study. If the study is delayed it is your responsibility to ensure that due account is taken of any new research information or developments which might affect the design or conduct of the study. Any amendments arising from this would need to be approved by the Committee before commencement of the study.
(iii) It is your responsibility to ensure that this study is conducted in accordance with the law. The Committee was concerned about your status at the study site and whether or not you would require an honorary contract. It also questioned whether
or not you had the appropriate authority from the nursing management to use nursing resources in the way proposed. You will, as you know, also require approval from the Research and Development Department at the Hospital. You should, therefore, address all these points before you commence the study.

(iv) It was not clear whether or not you would require access to medical notes. If so, and this is an essential requirement of the study, the information sheets and consent forms will require paragraphs providing authority to enable you to do this. If you do need to revise these documents please ensure that you send copies to the Ethics Committee.

(v) All consent should be written. Verbal consent is not acceptable.

(vi) The Committee should be provided with a copy of a report on the outcome of the study.

In the light of the comments at sub-paragraph (iii) above I have sent a copy of this letter to Dr also to who is the Research and Development Co-ordinator at the

Yours sincerely

[Signature]

Co-ordinator
05 June 2003

Ms Paula Reed
Anchor Down
10 Shepherds Hill
HASLEMERE
Surrey
GU27 2NF

Dear Ms Reed

**Dignity and the child in hospital (ACE/2003/47/EIHMS) – Fast Track**

I am writing to inform you that the Advisory Committee on Ethics has considered the above protocol under its ‘Fast Track’ procedure, and has approved it on the understanding that the Ethical Guidelines for Teaching and Research are observed and the following conditions are met:-

- Approval is obtained through the [Unis](#) Trust, and honorary contracts are in place prior to commencement of the research;
- The Protocol Cover Sheet is completed and returned to us, as requested in our letter of 22 May 2003.

For your information, and future reference, the Guidelines can be downloaded from the Committee’s website at [http://www.surrey.ac.uk/Surrey/ACE/](http://www.surrey.ac.uk/Surrey/ACE/).

This letter of approval relates only to the study specified in your research protocol (ACE/2003/47/EIHMS) – Fast Track. The Committee should be notified of any changes to the proposal, any adverse reactions, and if the study is terminated earlier than expected, with reasons.

I would be grateful if you would confirm, in writing, your acceptance of the conditions above, and enclose the appropriate documentation.

**Date of approval by the Advisory Committee on Ethics:** 05 June 2003

**Date of expiry of approval by the Advisory Committee on Ethics:** 04 June 2008

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Advisory Committee on Ethics

**Registry**

cc: Professor G Ferns, Chairman, ACE
Dignity of the Child

Paula Reed

Protocol

Submitted to XXXXX Children’s Hospice 3rd August 2005.

Background to the Study

The aim of this study is to explore the concept of dignity and children in a meaningful way, particularly for those who seek to promote dignity such as health care professionals. The focus of the study will be the dignity of children receiving health care in hospital and hospice/respite environments. I aim to study how dignity is experienced and expressed by the child.

The need to promote the dignity of individuals is accepted by health care workers, the media and is upheld in recent legislation. The requirement to promote dignity is explicit in policies and guidance to health care workers.

Empirical work that has been done focuses largely on related concepts such as privacy, self-esteem and confidentiality and mainly concerns adults, in particular older people. There remains a dearth of a common understanding about how dignity is best protected and promoted and indeed what dignity is, particularly with regard to children.

This study aims to address this gap in the research by taking an ethnographic approach in an attempt to explore the subjective experience of the child. In turn it may be used to inform policy and the practice of caring for children.

An ethnographic approach

Ethnography has traditionally been used by anthropologists as a way of understanding a culture that is different from their own. More recently, nurse researchers have used an ethnographic approach to explore health care issues in the context in which they occur (Lawler, J: Savage, J.). Naturalistic observation is key and is used to provide detailed studies of particular groups in a range of settings, with the ethnographer focusing on the interactions taking place and their meanings. Additional methods such as semi-structured interviews and documentary analysis augment observation. A characteristic of ethnography is that the methodology is iterative and evolving.

Pilot work.

I have undertaken an exploratory pilot study based on two children’s wards of a hospital situated in a deprived inner city area north east of London. I took an ethnographic approach, with the bulk of the data arising from participant observation. This was supplemented by informal interviews with staff and parents and the analysis of documentary evidence, such as the ward mission statement. Field notes were taken and later transcribed and sorted and resorted into themes.
The main purpose for the pilot study was to determine the feasibility and the appropriateness of an ethnographic approach to answer my research questions.

Additional pilot work has included:
- Semi structured interviews with adults who were hospitalized as children.
- Non-participant observation of children in a nursery (3-4 year olds)
- Participant observation of Year One children at school.

(A summary of the findings from the pilot work appear in Reed, P. et al. (2003) Promoting the Dignity of the Child in Hospital Nursing Ethics 10 (1) 67-76 attached).

The main phase of the research.

The research questions and themes were from the pilot study and provide the basis of observation and interview at the site(s) in the main phase of the fieldwork. These are:

- How can we understand dignity and children?
  - macro, meso, micro
  - body and containment
  - witness
  - power and control
  - social construction of children

- What is the subjective meaning of dignity for children?
  - methodological issues in hearing the voices of children
  - parents/carers

- What impact does the environment have on the dignity of children?
  - physical
  - ethos
  - people
  - social

The Fieldwork - ongoing

Approval for my study was given by the South West Surrey Local Research Ethics Committee in April 2003. Approval from the DGH and the University of Surrey was given subsequently. However, fieldwork was delayed until April 2005.

I have now completed four months of fieldwork at a District General Hospital, based on a children's ward. I have also spent some time in Out Patients and Accident and Emergency.

The Participants

The sample has been defined by the ward environment. There are three sets of participants: the children, parent/carers and staff.

The children
The ward take children from birth to sixteen. Currently all children are eligible for the study.
Parents/carers
Those parents of eligible children are invited to take part.

Staff
All staff on the ward and in related departments are invited to take part. I am hoping to recruit 15 staff members.

Siblings have not been included in this part of the study

Data collection
Prior to approaching any families I check with the nurse in charge that they think it is appropriate to do so. I have an Information Sheet for Parents, Carers and their Children (see attached). I give these out when I introduce myself to families. I explain a bit about the research and what I am interested in. I let them know that they will see me around and that I might write notes about what I see. If the child and/or their families are not happy for me to do this and do not give verbal consent. If a family member is not there to give consent for a child, then I do not observe them.

I have an Information Sheet for Staff (see attached) that I have given out at staff meetings and on an individual basis. Copies are available on the ward.

Consent forms.
If the child and/or family would like to be interviewed, then I ask them to complete consent forms (see attached).

Parent consent for interview (green)
Parental assent for their child to be interviewed (blue)
Child/young person's consent A. (white)
Child consent B. (white)
Staff consent (yellow)

I also use these forms if I would like to be around for a more focused observation such as a procedure e.g. blood test.

If the child and parent agree, I use a voice recorder. I transcribe recordings later for analysis.

Data Analysis
To date I have made observations of children (62) and their carers, including 19 taped interviews. I plan to complete 15 staff interviews.

I have started to analyse the data collected using qualitative data analysis techniques and constant comparative analysis. Grounded theory will be used to interpret the subjective experiences of the child and develop hypotheses about the nature of dignity in the child. Meticulous record keeping and clarity of the audit trail will demonstrate validity.

Proposal for additional fieldwork at XXXXX Children's Hospice
I would like to undertake some additional fieldwork XXXXX Children's Hospice to develop further and enrich the research I have completed already. In particular I would like to:

- Explore the ethos of making every day count in a child’s life that is limited by time. This will contrast with the acute hospital setting.
- Examine the nature of this contrasting environment to provide an invaluable and different perspective on the dignity of children.
- To hear the voices of the children of XXXXX and their families so that they can be represented in my research.

Proposed Design and Methodology

I propose to take an ethnographic approach as described above, although this can be modified to make it appropriate to this setting. I would take the role of participant observer at XXXXX for a period of time to be agreed. I currently visit the acute setting approximately twice a week which allows time for me to reflect and write up the observations and interviews. This could be modified to suit XXXXX, for example I could attend more or less intensively.

Participant observation will provide the basis in conjunction with documentary analysis and semi-structured interviews with staff, parents and children. Interviews will be recorded using a hand held voice recorder, if appropriate and agreement is given. I would be concentrating on the children and their interactions with one another, the staff, their parents and the environment and what they have to say about their experiences. My primary focus will be dignity and, as far as possible, interpreting the subjective experience of the children in the hospice/respite setting.

Activities such as draw and write, photos and toys could be used to facilitate interactions with children. I would like to invite and encourage children and their families to be as active as possible in the research process.

Field notes/tapes will be stored in a locked filing cabinet, they will be transcribed and sorted into themes. Data will be kept confidential and made anonymous with the ciphers held separately. Data will be held subject to the Data Protection Act and held up to five years in accordance with the act.

Participants

Children.

All children who are users of XXXXX will be eligible for the study. Non-verbal children will be eligible for observation. Children and their families will be excluded if they or their parents/guardians do not give consent, or I am requested not to include them by staff.

The sample will be defined by the population of XXXXX. The sampling is not statistically based and controls will not be required, due to the case study design. However, in a period of one month, collecting data for the equivalent of two days per week, I would expect to have a core, in-depth study group of 3 children and to have been in contact, through observation, with a population of approximately 10 children.
Parents/Carers
Those parents of children eligible to take part in the study will be invited to take part.

Staff
All staff, including volunteers, at XXXXX will be eligible for the study subject to their consent.

Analysis.
Data analysis will continue as described above.

Findings
I would like to share my findings with interested parties e.g. children and their families, staff and students in a variety of contexts e.g. posters, updates, teaching, discussions. This study will form the basis of a PhD thesis and papers for peer-reviewed journals.
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<th>Profession</th>
<th>Ethnicity</th>
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<td>F</td>
<td>Nurse</td>
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**Child Data**

- Screw put in thumb, graft from hip
- Jaw op.
- Post-op.
- Vomiting
- Jaw op.
- Foot op.
- Cerebral palsy - for tests
- Eye ? Haemangioma
- Tests
- Swollen eyes
- Downs syndrome - tooth extraction
- Toe operation
- In-patient since birth
- ? Chest infection
- Rash - I.V. antibiotics
- For theatre - on trolley
- Fractured tibia & fibula
- Bronchiolitis
- For chemotherapy
- Life-limited complex needs
- Pain in right leg
- Pains in legs for F-U blood tests
- Convulsion ? UTI
- Tooth extraction
- Jaundice for repeat blood tests
- Wheezing
- For appendicectomy
- Crohns disease - acute exacerbation
- Syringe and probing of tear duct
- Respiratory distress
- Cellulitis of eye
- Abdo. pain

**Appendix**

- Note 20.07
- Note 20.07
- Note 20.07
- Note & tape with mum 5.08
- Note & tape with patient 5.08
- Note & tape with patient 5.08
- Note & tape with nanny 5.08
- Note 5.08
- Note 20.07
- Note 20.07
- Note 21.07
- Note 21.07
- Note 20.09
- Note 22.09
- Note 22.09
- Note 23.09
- Note29.09
- Note 4.10
- Note 4.10.05
- Note & tape with mum 26.10 at home
- Note 9.11
- Note 9.11
- Note 9.11
- Note 7.12
- Note 7.12
- Note 7.12
- Note 7.12
- Note 7.12
- Note & tape with mum and patient 9.12
- Note 9.12 & tape 14.12 with patient
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- Note 14.12
- Note 14.12
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Dignity and the Child in Hospital
Appendix 9

Extract from interview with 1MN.

1MN was a newly qualified Children's Nurse who had had previous experience working in a residential setting for disabled children. In this extract we are coming to the end of a long interview of 45 minutes.

P: It's interesting because presumably you've had experience, considerable experience with children and young people who can't or find it difficult to express themselves verbally so, that's why I particularly asked you about babies...

1MN I think it's with all the children that I have worked with, especially with severe learning difficulties to being and to then working with people who are incredibly intelligent, but physically totally dependent, every single one of them has things that they like and they don't like. Children right across the autistic spectrum...! have various experience of, there's always something that they feel more comfortable with in some way, or not comfortable with and those elements are about their dignity. Taking say a child that has a blanket for comfort, taking that away from them is limiting their dignity and it's disrespecting them. Having in the past a long time ago individuals that say look that were quite challenging in their behaviour that maybe used electric wheelchairs. I've witnessed people turn the power off on the chair and completely remove this ability to move around as a punishment and whilst their behaviour perhaps did need to be addressed, removing their independence, or whatever independence they had is a complete disregard for their dignity and totally unacceptable. But in my mind, every single individual whether they have the cognitive level of 2 or 3 years of age and they're in the body of you know a twenty five year old, still has something, or some sense of dignity and we have to just try and you know establish what that is and be respectful of that. I know the baby issue is a very difficult one but there is no reason we can't set out, 'cos you know we do hold certain information and memories from the past and there are lots of experiences of older children that have a fear of needles and when you look back, the only experience they ever had was when they were in as a baby so its come from somewhere, but then there are different perspectives and different research around these areas but whilst it's a possibility, I would like to believe that you should try and be appreciative of it in your work.

Comment [P1]: Average 20 mins. Very reflexive/reflective
Comment [P2]: Dignity for all children, all individuals
Comment [P3]: Assumed level of understanding and self-awareness
Comment [P4]: Equating comfort with dignity
Comment [P5]: Denying independence and self-expression
Comment [P6]: Denial of autonomy
Comment [P7]: Degrees of dignity
Comment [P8]: No respect
Comment [P9]: Asserting individuality through disruption
Comment [P10]: Witness
Comment [P11]: What "people" (Witness)
Comment [P12]: Taking power away, bullying
Comment [P13]: Taking away autonomy (power)
Comment [P14]: Independence
Comment [P15]: Following their own agenda
Comment [P16]: Was he able to challenge, passivity of staff
Comment [P17]: Assumed lack of self-awareness and understanding
Comment [P18]: Ideas of embodiment
Comment [P19]: Socially and physically not a child
Comment [P20]: Work of the nurse to assess the individual
Comment [P21]: Respect
Comment [P22]: Rationale (emotional) for treating babies in a particular way - future oriented or demonstrating the real distress of babies
Comment [P23]: Adult based objective explanation
Comment [P24]: Is he saying objective and subjective in mind.
Dignity and the Child in Hospital
Appendix 10

Extract from interview with 7FN

7FN had been working as a qualified Children's Nurse for about a year on the ward. This extract comes from just two minutes into the interview.

P ...What would you understand by the term dignity?

7FN Um it's to do with privacy, giving them privacy as much as you can, um trying to give them their own space, but obviously there's difficulties with that as they are in here to be observed; but sort of um things that in situations where they could feel embarrassed, trying to prevent that um and just drawing round the curtains if they need privacy, giving them time to themselves with their families.

P: And so what, what comes to your mind when you think about dignity and children in particular?

7FN Do you mean in this specific area of work or...?

P: Yes, um before I asked you what you understood by the term dignity. Is there anything in particular about dignity and children that springs to mind?

7FN I think the importance of spending quality time, just them and their family, um I suppose for children in hospital here, the problems would be that they are around strangers and they are more vulnerable and just the importance of using curtains round beds, um, obviously not giving, be careful what you say in front of other people, information sharing, that sort of thing, just being careful who you speak to...

P. And do you think dignity changes as you grow up?

7FN Yes, at different ages, children require different types of dignity. Obviously when they go through adolescence, they are sort of going through puberty, it's sort of bearing in mind the embarrassment of that and I think it changes depending on how old they are.
Dignity and the Child in Hospital.
Appendix 11

Extract form interview with mcm4052 and cm4052 at home.

Cm4052 had undergone major surgery and chemotherapy from the age of two and a half. He was four at the time of the interview and was “in remission”. He had received treatment at both a specialist centre as well as at the study site. Cm4052 (C) was drawing a picture while he and his mother (M) and me (P) talked in the living room of his house. We had already been talking for approximately fifteen minutes at this point in the interview. The extract is reproduced from the verbatim transcript.

P. ...what would you understand by the term dignity anyway? As a general term?

M. A general term, I don’t know. I know what dignity is, I don’t know I can put it into words. Um, it’s somebody’s feeling of self worth.

C. Can you see that? The orange is brighter than the pink.

P. Umm, you’re doing lots of experiments with the colours aren’t you?

M. Umm yes feeling of self worth and their part of the whole game plan, not just being done to.

C. Can you see this, Mummy can you see this?

M. OK, go on, see if you can draw a line in between the two.

P. What comes to your mind when you think about dignity and children?

M. Well, treating them as, they are part of what is happening and they are human beings just as adults like to be treated...

C. Can you see this, Mummy can you see this?

M. And they should be spoken to not above or round(smiling)
Across crocodile lake…

And I think older children in terms of privacy, having privacy I think, I can imagine teenagers on a ward don't really want to be pulled around and poked and prodded unnecessarily. I think that's part of being, having some dignity.

M. Yes, I think your perceptions. I mean I think children this age do not mind running around naked, whereas older children and adults would be bothered by something like that. That's just one, fairly poor example.

P. Ummm. You said a bit about this. Do you think dignity changes as you grow up?

M. And then you have your ultrasound done

C. No when I have my tummy done and needs…. (gesturing).

M. Oh when you have your X ray and you need to take a deep breath (takes a deep breath inwards) don't you?

C. Umm

P. So you've had to learn to keep still

C. And sometimes it frightens me doesn’t it?

M. And the noise from the X ray.

C. Yes

M. So yes learning, to do certain things and be compliant when needed I think.
Implications for policy and practice

In this section I outline some of the implications for policy and practice arising from the research “Dignity and the Child in Hospital”.

1. If children are unaware of the social norms of promoting and protecting dignity, they should be treated “as if” they had this awareness. It should not be assumed that dignity is not relevant, but be afforded the same attention to privacy and exposure as any other patient.

2. Nurses need preparation to be involved with the procedures undertaken on children. The emotional impact needs to be recognized and strategies offered and learned to manage, rather than deny, emotions.

3. Doctors and nursing require education about the needs of children with a variety of special needs and disabilities, especially those with emotional and learning needs. This includes learning negotiation and interpersonal skills to facilitate good working relationships with the parents and child.

4. The voice of the child can become muted in three way communication. Staff need to be aware that this can occur and remind parents where necessary.

5. Parents are frequently unclear as to their role when in hospital with their child. Staff should offer guidance, supported with written information, and be prepared to negotiate the optimum parental role for the child.
6. There needs to be recognition of the importance for children to have control over how they present themselves. Alternatives to hospital gowns could be considered.

7. The sociability of children can be acknowledged by simple measures such as introducing children to those in the bed next to them and placing children of a similar age together.

8. The embarrassment of boys needs to be acknowledged. They may prefer to be cared for/examined by a male member of staff.

9. Children with severe and chronic illness can spend a considerable proportion of their lives in hospital, but not be eligible to benefit from the resources of a hospice. The care of these children in District General Hospital facilities needs to be reviewed.

10. Staff need to become more aware of their own behaviours in exacerbating the vulnerability of babies and those with special needs, through education and reflective practice.

11. Respect for children in their parents includes staff valuing their time. Children and parents should be given accurate information on waiting times and appointments and procedures scheduled with their agreement.

12. The uncertainty and anxieties of parents, including their need for visual and auditory privacy needs to be recognized and addressed particularly in the Ambulatory Care, or pre-admission area.

13. Staff should be encouraged to reflect upon and challenge the notion of best interest and “holding down” to ensure that the needs of the child take precedence.
14. A commitment to the prevention and alleviation of pain in all children including infants should be at the heart of policy and practice. This includes the use of current the evidence based guidelines on the use of analgesia by all staff.

15. Staff and parents should treat naso-gastric tubes and drains as if part of the child’s body liable to cause embarrassment and handle them discretely after first asking the child.

16. Policies relating to the use of children in teaching sessions or examinations should be reviewed. Willingness to take part may be dependent upon desensitization (habituation) to bodily exposures.

17. Parents and children should be seen away from public areas wherever possible. It is rarely possible to predict the course of an interview or the reaction and sensitivities of the child/parent.

18. An understanding and debate of dignity needs to assume a central position in the education of medical, nursing and other hospital staff.

19. Children and their families valued highly a sense of being human and feeling that they mattered. They need acknowledgment, recognition of their individuality and needs and a commitment to engage with them in their care.