Children's and Young People's Experiences of Being in Hospital: Disruption, Uncertainty, Powerlessness and Restoring Equilibrium

by

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ABSTRACT

Whilst the Government has made explicit its stance towards identifying and taking into account the views of children and young people as service users it appears, within some hospital settings, that few openings are available to many children and young people, particularly those with learning or physical disabilities and acute illnesses.

This qualitative study used an ethnographic approach to explore 46 children and young people's experiences of being in hospital. Data were collected within the hospital setting through unstructured participatory observation and semi-structured interviews alongside a variety of methods and activity based techniques. The data were collected and analysed concurrently in order to explore emerging themes in the analysis. The children and young people were diverse in terms of age ranges, experience of being in hospital and illness, with some being acutely ill and others having long term chronic illness.

The findings revealed that children and young people experienced disruption due to being in hospital. This was experienced as a complex variety of factors, situations and people impacting upon their experiences. Interwoven within this disruption were feelings of powerlessness and uncertainty. Children and young people described experiencing disruption, uncertainty and powerlessness in terms of being in hospital, being ill and undergoing treatment and experiences of care and caring. In order to reduce these experiences children and young people undertook a range of strategies and actions in an attempt to restore equilibrium including "influencing", "accepting", "acting" and "positivity". Within this study I bring together for the first time the ways in which being in hospital creates disruption for children and young people and their agency and capacity in mediating their resultant experiences of powerlessness and uncertainty. I also provide an explanation for the ways in which children and young people experience disruption and restore equilibrium by drawing on Bronfenbrenner's work.

The findings have implications for children's nursing in terms of quality and delivery of care for children and young people in hospital.

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CHAPTER 1:
INTRODUCTION

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This is a study of children's and young people's[1] experiences of being in a children's hospital in the North of England. As a children's nurse working clinically I have a strong commitment to enhancing the care I am able to provide. Within my past clinical experience I have cared for children and young people alongside parents, other family members and members of the multi disciplinary team. Consequently I have an awareness of the multiple factors impacting upon experiences of being in hospital; those of being ill, undergoing treatment and being cared for by a wide group of people, all with different knowledge and skills, set against a backdrop of the ward environment within the wide and diverse setting of children's services. However, as I focused more upon this, my awareness of the invisibility of children's and young people's perspectives within nursing research as a whole was highlighted. Thus my awareness was from my own perspective as a children's nurse and not from the perceptions of children and young people themselves. The study arose out of my concern that children's and young people's perspectives of being in hospital, and those elements which impacted most directly upon their experiences, were largely unknown and unexplored. Initially, I began to explore the ways in which parents' participation in the care of their child whilst in the hospital setting might enhance children's and young people's experiences. However, I began to realise that this was only a small part of the overall experience of being in hospital and was led by the children and young people themselves to explore, from their perspectives, those issues and elements that impacted most directly upon their experiences.

Children have been described as the "silent consumers of healthcare" (Carter 1998) and certain groups of children and young people, particularly those with complex needs and disabilities, have been identified as being at particular risk of exclusion from consultation (Beresford 1997, Ward 1997). This is of particular concern in light of work which suggests that the accounts of parents and other adults, extensively used as proxies for children, may not accurately reflect the perceptions of children themselves (Hart and Chesson 1998). Seeking children's and young people's views is important not only for individual children and their families but also for the future of children's services. Unless children's perceptions are known, services cannot respond to their needs and

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[1] Throughout the thesis I use the term "children and young people" in order to acknowledge the difference between these two groups and to be respectful of these differences rather than just use the encompassing term "children".

improvements to achieve high quality care cannot be instigated. I believe that eliciting the views of children and young people in terms of their hospital experiences will improve the care I, and other nurses, am able to provide and ensure that is rooted in those elements that they themselves believe to be important.

Whilst the Government has made clear its strong stance towards identifying the views of all service users, including children and young people, the opportunities open to this important group to act as consumers of care seems unclear. Such concerns have been identified as long as thirteen years ago following the publication of Government papers such as The Patient's Charter: Services for Children and Young People (Department of Health 1996). Much more recently, Our Health, Our Care, Our Say White Paper (Department of Health 2006) and the National Service Framework for Children, Young People and Maternity Services (Department of Health 2004) have made explicit that service users should be consulted and involved in the design of future services and have made clear the importance of taking into account the views of children and young people. However, upon further reflection and drawing upon direct personal experience it became apparent that few openings are made available to many children and young people, particularly those with learning disabilities and short term acute illnesses, to express their views as service users within some hospital settings. This is of concern in relation to those Government recommendations that emphasise the importance of listening and responding to children and young people with disabilities (Department of Health 2004). The ways in which this impinges upon the experiences of children and young people in hospital raises important questions which, I believed, warranted exploration.

This study about children and young people with the aim of enhancing care and understanding is presented within eleven chapters. Within this study I have adopted a reflexive approach. In maintaining a reflective dialogue, throughout the thesis I write in the first person in order to best illustrate my own thoughts and interpretations. Children and young people's perceptions are at the heart of my study and central to everything I think is important and value as an experienced and expert children's nurse and as a developing academic children's nurse. Therefore, I have made a conscious and deliberate decision to start each findings chapter with a quote from one of the children or young people who participated in my study.

In this first chapter I briefly set the scene and provide an overview of the structure of the thesis. In Chapter 2 part 1, I explore the traditional, dominant Western conceptualisations of childhood within the realms of sociology, psychology and socio-ecology and relate these to both healthcare and research with children. I follow this with an exploration of the re-conceptualisation of childhood and apply this to both children's nursing practice and research with children and young people. In part 2, I outline the literature around children's and young people's experiences of being in hospital, being ill and undergoing treatment, and receiving care. Within this chapter I introduce the work of Bronfenbrenner (1979) and describe the way in which his theoretical model forms the basis for this study.

Within Chapter 3 I describe the methodology of the study, including my choice of symbolic interactionism as the theoretical framework. I also provide my rationale for using qualitative and ethnographic approaches. In Chapter 4 I describe the unstructured participatory observation and semi-structured interviews interspersed with age-appropriate child centred methods I used, and acknowledge the ethical considerations appertaining to undertaking research with children and young people. In this chapter I also outline the analytical approach used alongside my interpretation and representation of children's and young people's responses.

Within the next chapter I describe the hospital and ward settings, the staff, daily life in the ward and the children and young people who participated in the study in order to set the scene prior to presenting the findings in Chapters 6 to 8.

In Chapter 6 I describe children's and young people's experiences of being in hospital, including their feelings around being in the hospital setting, the social order of the ward and experiences of the ward routine and organisation. In Chapter 7 I explore experiences of being ill and undergoing treatment including the restrictions of being both acutely and chronically ill and feeling different, alongside the invasions and intrusions of undergoing treatment. Chapter 8 examines children's and young people's experiences of care and caring including being cared for by nurses, being cared for by parents, caring for oneself and children and young people as experts in their own care.

Next, in Chapters 9 and 10 I discuss and theorise the overall themes of disruption, uncertainty, powerlessness and restoring equilibrium highlighted within the experiences of children and young people, and its resonance with work of Bronfenbrenner, presenting my original contribution to knowledge. Lastly, in Chapter 11 I consider the limitations and implications for practice that arise from my study, make recommendations for future research, reflect on the methods used and outline strategies for dissemination.

CHAPTER 2:
REVIEW OF THE LITERATURE

CHAPTER 2: REVIEW OF THE LITERATURE

> "Everybody thinks that they know what it's like to be in hospital, but it's only people like me and the other children that are here that really know" (Violet (44), aged 9 years).

Introduction

In order to understand present practices in relation to the rights and position of children and young people within society, healthcare and research, it is important to reflect upon popular Western constructions of childhood which draw a multitude of assumptions about childhood and children into coherent patterns.

This chapter is divided into two parts. In part one I explore the theoretical traditional, dominant Western conceptualisations of childhood as espoused by sociology, psychology and socio-ecology and relate these to both healthcare and research with children. This is followed by an exploration of the re-conceptualisation of childhood and an application of the aforementioned conceptualisations to both children's nursing practice and research with children and young people. In part two I outline the literature around children's and young people's experiences of being in hospital, being ill and undergoing treatment and care which add to the building of a theory of children's nursing.

For the purposes of the literature review an Optimal Search Strategy was undertaken. Information was obtained from journals, books, abstracts, grey literature, networking and the World Wide Web. In order to gain an overview of children's and young people's perceptions of hospitalisation, key search terms (for example., child health, child health services, children's nursing care, paediatric nursing care, experiences of children, experiences of young people, illness experiences, hospital experiences) were entered into a range of databases and Medical Subject Heading (MeSH) sought. The following databases were accessed: Medline, Cinahl, PsycInfo, ASSIA, CAREDATA and Web of Science. Policy sites were also accessed including Department of Health and local health authority sites. Dates entered into the search were 1999-2009. The search was limited to twenty years as this encompasses the point in time from which children's perspectives started to be widely published. The MeSH terms were identified and searched until saturated and a range of filters used including focusing and Boolean.

Studies were eligible for inclusion in the review if they involved children and young people between birth to 19 years, were in English and used qualitative research methods. The search was limited to qualitative studies as these best provide opportunities for children's and young people's agency to be presented. The studies involving children and adults presented data from children and young people separately. In line with my own conceptualisation of children and the principles which guide this study, this review focuses upon the findings from studies which have derived data from children and young people themselves, rather than eliciting adults' beliefs about what is important to children and young people.

Western conceptualisations of childhood

Introduction

In this section I explore the dominant Western conceptualisations of childhood as proposed by sociology, psychology and socio-ecology, applying these to healthcare and research with children. I follow this with an exploration of the re-conceptualisation of childhood.

A sociological perspective

As James (1998: 99) describes, for contemporary Western children and young people, cultural imaginings have characterised a "period of lack of responsibility with rights to protection and training but not to autonomy. It represents a particular mythologising of childhood through gradually entwining the concept of the child with ideas of otherness, naturalness, innocence, and a vulnerable dependence." Consistent with the image of innocence, childhood is construed as a happy and carefree time of life (Berman 2003). However, as Jenks (1996) argues, commonly used adjectives to describe children such as innocent, vulnerable and in need of protection present a misleading depiction of the realities in children's lives. One such misrepresentation is that children are not supposed to become seriously ill or have to undergo aggressive and painful treatments. However, that is not the reality for many children and young people.

That all dominant Western conceptualisations of childhood are conceived and defined by adults only serves to reinforce the powerful position of adults whilst sublimating children's position further. Many reasons exist for these "adultist" perspectives. Historically, children and young people as a "powerless" group rarely wrote their own personal history (Richman and Skidmore 2000). Therefore, just as history can be seen to be a construction rather than an absolute truth, "we must assume that if it were possible, historical accounts written from the child's point of view by children and young people themselves might reveal radically different perspectives" (Wyse and Hawtin 2000: 129). As Oakley (1994: 23) argues:

> "if children have no place of their own in their theory, and do not give rise to their own concepts, their value is ... in their status as would-be adults'... The primary determinant of concepts of childhood and theories about children is the cultural emphasis on adulthood as a project of individual entity. The result of this, from children's point of view, is often an uncomfortable fitting of their experiences into a framework not derived from them".

These perceptions of children and childhood can impact in various ways on how the rights of children are put into practice. Hardman (1973) suggested that children have been "muted" in the past, their perspectives not being heard by adults due to their positions of authority and power over children, thus effectively silencing them (James and James 2008). Traditionally in Western society children are viewed as the property of their parents who are invested with the rights seen as necessary to carry out this role. Such an approach exemplifies the powerful position of adults with associated resultant powerlessness for children. Yet, the perceptions of some adults rendering children as essentially irrational, irresponsible and incapable of making informed choices on matters of concern to them, still reflected to a large extent in legislation, reinforces popular conceptualisations of children as being dependent and incompetent. Meanwhile, a consequence of the social and cultural construction of childhood's innocence is that increasingly children in Western societies are marginalised from the activities and concerns of the adult world (James and James 2008). This occurs under the guise of their protection since prevalent beliefs about children's limited knowledge and understanding have led to notions of children being vulnerable (James and James 2008). These beliefs result in an overwhelming depiction of children and young people as powerless within society which, by necessity, impact upon all areas of children's lives.

Despite considerable evidence refuting myths that children are innocent, passive or incompetent (see for example, James and James 2008), this notion has been seen to persist. It has been argued that a portrayal of children as being protected from the harshness of adult life erases the extensive range of experiences and complexities children encounter in their daily lives, failing to reveal the ways in which social and cultural institutions shape children's experiences (Berman 2003). An important aspect of the innocent myth Berman (2003), argues is that this suggests that children exist apart from the political realities that affect others. However, this can clearly be seen to be not so. For example, a recent newspaper editorial entitled "Children not seen, not heard" (The Guardian 2009) listed the high prevalence of mental illness, homelessness and sexual exploitation of children in care in the UK. Similarly, the UNICEF document "The State of the World's Children" (2009) depicts a picture of early marriage, HIV and AIDS, sexual violence and other gender related abuses impacting upon many children's lives throughout the world.

These beliefs about children's incompetence, powerlessness and dependency can also impact upon the position of children and young people within the health arena, where their health is viewed as an adult problem. Children's health has been seen as the responsibility of adults, rather than in part their own and James (1998: 101) argues that this is a clear illustration of the manner in which constructs of childhood have worked to shape the "social and institutional practices of medicine in relation to children". Thus, the traditional and often espoused view that children and young people, not yet mature, must necessarily be incompetent in self care and that, in consequence, it is adults who must stand guard over their health (Mayall, Bendelow and Barker 1997, Mayall 1996) is indicative of such an instance. Adults are presumed competent to make health care decisions whilst children are often presumed incompetent and adults are allowed to refuse treatment whilst, most usually, children cannot (Bricher 2000). For health care professionals themselves, the fact that they are adults and hold power over children can prove difficult if they are not to subsume children's interests. As Darbyshire (1994) argues, in the practice setting professional knowledge is privileged and parental discourse is secondary only to professional knowledge.

Children in hospital are often vulnerable due to their illness and have little control over events happening to them (Bricher 2000), with studies indicating that loss of control and dependence are experienced by children and young people in hospital (Coyne 2006, 2003, Gusella, Ward and Butler 1998, Thompson 1994). Taking children and young people out of their familiar everyday environments and putting them into the unfamiliar hospital setting compounds any power bases they may have and increases their dependence on others. Hospitalisation can disrupt the lives of children and young people in terms of their everyday routines (Wise 2002) and sleep and rest patterns

(Lindeke and Johnson 2006). Illness itself can also cause disruption to children's normal lives (Forsner, Jansson and Sorlie 2005b) and to their sense of well being (Coyne 2006). McCormick (2002) suggests that a state of uncertainty is a major component of all illness experience. Treatments in hospital may also often render children powerless and further dependent upon their parents or nurses. However, this is not to say that this reflects upon children's everyday normal capacities and capabilities and that they are passive within their hospital experience.

It has been suggested that the adult-centeredness of Western society and the unequal power relations that exist between adults and children are duplicated within research (Punch 2002, Harden et al 2000, Morrow and Richards 1996). Assumptions that children are incompetent and lacking in capability have rendered children's perspectives as lacking in value or not credible until recently (Carter 2009). Meanwhile within healthcare, Berman (2003) suggests that health service professionals themselves may limit children's participation in discussing important, or potentially upsetting issues, under the guise of protecting them. As Alderson (1995) comments, within healthcare, the tension between children's rights to participation and children's protection can be at its most extreme. However, in research terms a stance of protectionism can result in children being excluded, thus marginalising children's interests (Carter 2009). Carter (2009) comments that children's participation within research is set within primarily adult-dominated discourses viewing children as naturally vulnerable. Historically this is reflected within research which obtained children's views from either objective measures or from proxy accounts by adults believed to know children's perspectives, such as parents or nurses (Faux, Walsh and Deatrick 1988). As a consequence, children's and young people's views and perspectives have been largely subsumed within those of "the family" or other powerful adult members of society, and more importantly, presumed to be congruent within the past (Qvortrup 1994). Two fundamental elements underpinned such an approach; firstly, a belief that adults best knew the needs of children and young people and secondly, that the responses and views of children and young people were most likely to be inaccurate. Both result in the knowledge about children and young people being deeply and unreflectively centred around the experiences of adults. It is imperative to note that while ever children and young people have been conceptualised in this way, and their perspectives ignored within the health field, the congruency, or otherwise, of their experiences could never be either confirmed or refuted.

Other dominant views have depicted childhood as a temporary state with efforts directed solely to growing up and becoming adults (Berman 2003) and thus positioning children as a separate group "other" to adults (Carter, Marshall and Sanders 2009). For example, Jenks (1996) comments that futurity is fundamental to understanding many conventional adult views of, and attitudes towards, children which are encapsulated in the notion of children as "becoming" rather than being. Most notably, this approach fails to recognise childhood as its own entity. Instead it is spectacularly undervalued and considered only worthy through the potentiality children and young people may offer to life as adults. Thus a focus on futurity serves to diminish the importance of children's perspectives in the present (James and James 2008). Immediately such an approach theorises children and young people as inadequate before their passage to adulthood is completed, once again reflecting the predominantly powerful position of adults in society.

However, where childhood is viewed as a pre-cursor to adulthood it is important to recognise that the adult world is not always pleasant towards children. This can be seen within hospital, where adults in their role as health professionals may be allowed to hurt and isolate children. At this time the child's world is not coherent; instead children may lose their identity and are not protected from the hurts associated with being in hospital, being ill and undergoing treatment. Importantly also, this discourse creates particular problems for children and young people in offering visions of what they are or should be in adult terms (James 1995). This is of particular significance to some children, such as those with cognitive impairments who will never be completely "adult" in the sense of gaining responsibilities and commitments as they grow up (Carter 2009).

The assumption that children are a separate group, "other" to adults, is reflected both within the hospital setting where children are seen as not yet adults yet treated in the same way as adults regardless of age and gender. Recently, debate has taken place within research where the need to create special research techniques for children constructs children as "other" in methodological terms with a need to use different methods (Kirk 2007). This may diminish the position of children in research by questioning their competence and assuming that they are not able to engage by the methods used with adults (Punch 2002, Hill 1997).

Alongside being "other" to adults, sociology has traditionally viewed childhood as a largely undifferentiated and generational space that could be subsumed within the family. This perspective on childhood has been reinforced by developmental psychology as a developmental phase in the life course, typified by certain biological commonalities broadly linked to chronological age. It has been argued that a central aspect of the marginalisation of children is the tendency to examine childhood as a single entity devoid of race, class or gender thus effectively concealing the realities of children's and young people's lives (Berman 2003). However, as James and James (2008) comment, a notion of a universal and homogenous childhood distorts the reality of the lives of many children around the world. Childhood must be located in its social, historical, geographical and cultural contexts in order to be understood in terms of the diverse experiences of children (James and James 2008). And yet characterisations of childhood as a homogenous group with shared experiences deny children a voice and implicitly sustain existing power relationships between children and adults, perpetuating the process of disempowerment and marginalisation (Berman 2003). Where children are viewed as a homogenous group, devoid of gender, race or class, the reality of gender oppression, inequality and discrimination are effectively concealed (Berman 2003). Presenting childhood as part of one homogenous group has been used in the past to contrast the differences between childhood and adulthood (Davis 1998). Such an approach reinforces the "other-ness" of children whilst failing to acknowledge the diversity and multiplicity of their lives and the range of their capacities (Carter 2009).

Historically this marginalisation of children has extended to research (Carter, in press). It has been noted that older young people, most frequently girls, are involved in research (Kirby and Bryson 2002) whereas younger children (Sloper and Lightfoot 2003), young people from ethnic minority groups and socially excluded groups (McNeish and Newman 2002), disabled young people (Kelly 2005) and those with severe impairments (Lightfoot and Sloper 2003) are less likely to be included.

Cocks (2006) argues that "a hierarchy of marginalisation exists with some children being less likely to be invited to participate …". For example, some individuals regarded as "passive and either not worth hearing or not able to be heard", including those with a mental illness, learning disabilities and indeed children, will be less likely to be included in health care research (Sartain, Clarke and Heyman 2000: 920). As a result however, some groups of children, for example those with either mental health problems or learning disabilities may be doubly marginalised in research terms. For example, Rabibee, Sloper and Beresford (2005) comment that children who do not use speech to communicate continue to be defined by not what they can do but rather what they cannot do, whilst children who are sick and considered extra vulnerable may be at increased risk of having their views discredited or ignored (Coyne 2006).

Within research, the view of children and young people as a homogenous group suggests that a "one size fits all" approach could be used (Carter 2009) instead of recognising children as a highly differentiated group with different methodological implications (Hill 1997). However, acknowledging the need to explore the experiences of children and young people across a range of illnesses and disability experiences thus resisting reducing children to, or merely identifying them with, their illness (Blumenreich 2004) is important if the diversity of children's lives is to be explored. As Carter (2009) highlights, failing to be inclusive within children's research silences the voices of some children.

In this section I have explored Western conceptualisations of childhood as espoused by sociology. In the next section I explore these childhood conceptualisations from a developmental psychology perspective.

Perspectives from developmental psychology

In the past developmental psychology presented a conceptualisation of childhood focused around development (Kirk 2007). The single most influential figure within this paradigm is Piaget whose work is arguably the most accepted and absolute image of childhood to be encountered (James, Jenks and Prout 2001), although now also hugely contested. This perspective, based on natural growth and viewing development in terms of a progression, conceptualised children as incompetent, immature, passive, incomplete and conforming as objects within a one-way socialisation process (James and Prout 1997, Waksler 1991). Thus from Piaget's perspective, age and competence are intertwined with the child being determined by his/her developing body. As a consequence, James and James (2008) argue, childhood came to be seen as the epitome of lack of competence with adulthood as the model of competence. This necessarily places children as social objects in the process of becoming adults, rather than being children. Children are often negatively defined in relation to adult capabilities (Carter 2009). As per sociological perspectives on childhood, Piaget's view of children and childhood perpetuates an image of children as incompetent, thereby establishing and maintaining a power divide between adults and children (Bricher 1999). Competence is regarded by many adults as being intimately linked to chronological age. James and James (2008) argue that this is as a result of developmental psychology's implicit emphasis on children's incompetence, immaturity and dependency. James and James (2008) argue that there is no necessary link between age and competence and that even young children can be morally competent and capable of making informed decisions. Because of this perceived innocence and lack of competence, all children are seen as vulnerable and childhood as a period of inherent vulnerability (James and James 2008). This thinking is implicit in psychological development which implies that because the child is not yet fully developed he/she is vulnerable to any influences that may affect their development processes (James and James 2008).

Certain criticisms have been directed towards developmental psychology's conceptualisations of children. The first is that children are conceptualised and researched as though they have an existence aside from the context in which they live; that context, whether community, research setting or time can be "controlled" allowing the "true child to emerge" (Hogan 2006: 26). Secondly, that child development is regular and standard, progressing naturally in a linear fashion, and thus an uncomfortable fit with an image of childhood as being fragmented and multi-directional (Hogan 2006). This point has been expounded by James and James (2008) who in seeking to understand children and how they experience their childhoods emphasise that the significance of differences in children's development must be recognised. They argue that it has become clear that there is no single, pre-determined model of psychological development that holds true for all children in all settings (James and James 2008). Thirdly, children within this paradigm have been viewed as having less to offer research than adults themselves due to their being "adults in the making". Thus their positioning as "becomings" rather than as "beings" lends to children being viewed as passive and dependent, and unreliable informants. In research terms, reports by parents or other adults would be considered to be the "gold standard" and typically used to judge the accuracy and value of the child report (Hodges 1993). A view of children as living in a fantasy world, being highly suggestible, prone to making up stories and having age dependent competencies depicts them as being unreliable informants, until as Hogan comments "they are approaching adulthood, when they can offer an adult-like perspective in adult language" (Hogan 2006: 27). Sociologists themselves meanwhile, have criticised psychology for its focus upon age related competencies, rather than subjective experience, at the expense of exploring what it means to be a child, leading to a detached and impoverished understanding of children's lives (Hogan 2006).

Even those within the field themselves, (see for example, psychologist John Flavell), have conceded that developmental psychology had learned little of children's subjective experiences, instead being limited to age linked competencies, knowledge acquisition and some aspects of social and non-social behaviour:

> "We have seldom tried to infer what it is like to be them and what the world seems like to them, given what they have and have not achieved cognitively. When knowledge and abilities are subtracted from the totality of what could legitimately be called "cognitive", an important remainder is surely the person's subjective experience: how self and world seem and feel to that person, given that knowledge and those abilities" (Flavell 1992: 1003).

As already highlighted, Piaget's theories themselves are now widely contested. For example, Archard (1993) identified Piaget's ideal of adult cognitive competence as peculiarly Western with the field of psychology itself acknowledging its failure to take account of the impact of social and cultural contexts upon the development of children (Woodhead 1997). Clearly, children cannot be viewed as a homogenous group since their abilities and level of functioning at any given age are far from universal. For example, the application of a base stage approach as espoused by Piaget to children's understanding of illness has been criticised by Sigelman et al (1993) with studies in existence revealing that children with a chronic illness have a greater understanding of illness than those without (Crisp, Ungerer and Goodnow 1996). Ironically, Piaget's principal method of enquiry, including the clinical interview and his close observations of the everyday lives of children, resonate strongly with the methods espoused by the new social studies of childhood and demonstrate an acknowledgement of the perspectives of children themselves (Hogan 2006).

Despite the criticisms put forward however, it is clear that the work of Piaget has "instilled a deep-seated positivism and rigid empiricism into ... contemporary understandings of the child" (James, Jenks and Prout 2001: 19). Piaget described his stage theories as real and directly reflecting "actual psychological activities" in the child's mind (Piaget 1957). Yet as Alderson (1993: 64) argues:

> " ... theories are only patterns describing experience, whether in their narrow sense as hypotheses tested by research, or in their broad sense of working assumptions. Despite recent understanding of children's early intellectual and moral maturing, outdated theories continue to dominate professional and public beliefs about childhood. Developmental theories possibly remain popular because they support psychologists' claim to unique and powerful expertise in testing and classifying children, and interpreting between "the child's world" and "the adult world".

This point has been expanded further by Alderson and Montgomery (1996) who conclude that the theories of Piaget are based on studies which both greatly under-estimated children's capacities and produced invalid evidence. The pervasiveness of the developmental model has been noted in terms of the use of chronological age in the organisation of children and the assessment of children's development through the use of standardised tests (James, Jenks and Prout 1998). Meanwhile, in research terms, certain ideas about children's psychological development can allow them to be more easily disqualified as participants of research (Alldred 2000). For instance, this approach is still pervasive in research terms where younger children are believed to be unlikely to produce "useful" data (Hill 1997). Similarly, Piaget's developmental theory approach renders children as mere objects of study through a failure to incorporate children's own views and perspectives into theory thus serving to objectify children and young people and deny their subjectivity. This has led critics to argue that the child in developmental psychology research "is an object rather than subject of scientific research, in that researchers expect to come to know its essential qualities through rigorous examination of its properties, under controlled circumstances" (Hogan 2006: 25). Further similarities appear to exist between Piagetian notions of the naturally developing child (James and Prout 1990) and ideas prominent within the dominant medical discourses of childhood (Shakespeare and Watson 1998). As Davis, Watson and Cunningham-Burley (2000: 205) comment:

> "Both notions pathologise children who do not achieve universal standardised developmental targets and identify disablement with impairment. They show little awareness of the possibility that these concepts are socially and culturally defined. As a consequence, academic research has been preoccupied with differentiating children on the basis of their impairments … and providing advice from a medical and developmental perspective about good practice for working with children with specific impairments".

However, despite Piaget's work being widely disputed, the implications of Piaget's theories upon children's lives remain visible. Indeed, developmental psychology as a science has firmly colonised childhood within medical, educational and governmental agencies. The powerful position of adults within this construct is clear. Child development is a body of knowledge constructed by adults for other adults to use in order to make sense of, regulate and promote children's lives. In fact, most often children's actions and thoughts are interpreted against models of psychological processes, stages of relative competence and/or deviations from normality, thus reflecting the powerful position of adult on children's lives. As Carter (2004) describes in relation to experiences of pain, dominant medical discourses may have little resonance for those experiencing pain themselves.

This section has explored Western conceptualisations of childhood from a developmental psychology perspective. I next explore conceptualisations of childhood from a socio-ecological standpoint.

Socio-ecological conceptualisations of childhood

As one of the challenges to mainstream models in developmental psychology, socio-ecological approaches to childhood contributed to a shift away from the child as a research object, thus contributing to the emergence of social constructionism. One of the main proponents of the socio-ecological approach to childhood was Urie Bronfenbrenner (1917-2005), a renowned Russian-born, American psychologist, known for his work in child development. Regarded as one of the world's leading scholars in the field of developmental psychology, Bronfenbrenner's groundbreaking contribution was his Ecological Systems Theory, making him one of the first psychologists to adopt a holistic perspective on human development. The major statement of this theory, The Ecology of Human Development (1979), has had widespread influence on the ways in which social scientists approach the study of human beings and their environments.

As a result of Bronfenbrenner's groundbreaking work in socio-ecology, the importance of environments, from the family through to economic and political structures, are now viewed as part of the life course from childhood through to adulthood, breaking down barriers among the social sciences and building bridges between the disciplines. Indeed, it has been argued that socio-ecological approaches may bridge the divide between psychological and sociological approaches to children by allowing us to understand what a child brings to a setting as well as what the social world provides for that setting (Greene and Hogan 2006).

Bronfenbrenner is also known as a co-founder for the Head Start programme for disadvantaged pre-school children in the USA, the American precursor to Sure Start in the UK. His work not only transformed the way in which social and behavioural scientists approach the study of human beings and their environments but also led to new directions in research and the design and application of programmes and policies affecting the wellbeing of children and families. The instigation of the Sure Start programme in the UK demonstrates the influence of Bronfenbrenner's ecological approach on contemporary thinking within the current care of children.

Bronfenbrenner proposed that children grow up in a social world in which social and temporal context plays a critical role but that they are active agents in shaping their own lives, arguing that research in laboratories cannot represent the real worlds and everyday experiences of children. Thus from Bronfenbrenner's viewpoint, for research to be ecologically valid it must take place in real life settings and aim to capture the experiences of children.

Bronfenbrenner's perspective conceives the world as a series of interactive ecological levels and is based upon the combination of the child's biological disposition and environmental forces coming together to shape the child's experiences. Thus, within this model, children and young people, parents, family, friends, ward, hospital and the context of children's services take up place within the different layers. Bronfenbrenner's approach has been depicted pictorially in a series of concentric circles (see figure 2.1) where the smallest circle in the centre of the others is the child. Boemmel and Briscoe (2001) describe the child as being an egg nested within other environments that are also nested within each other.

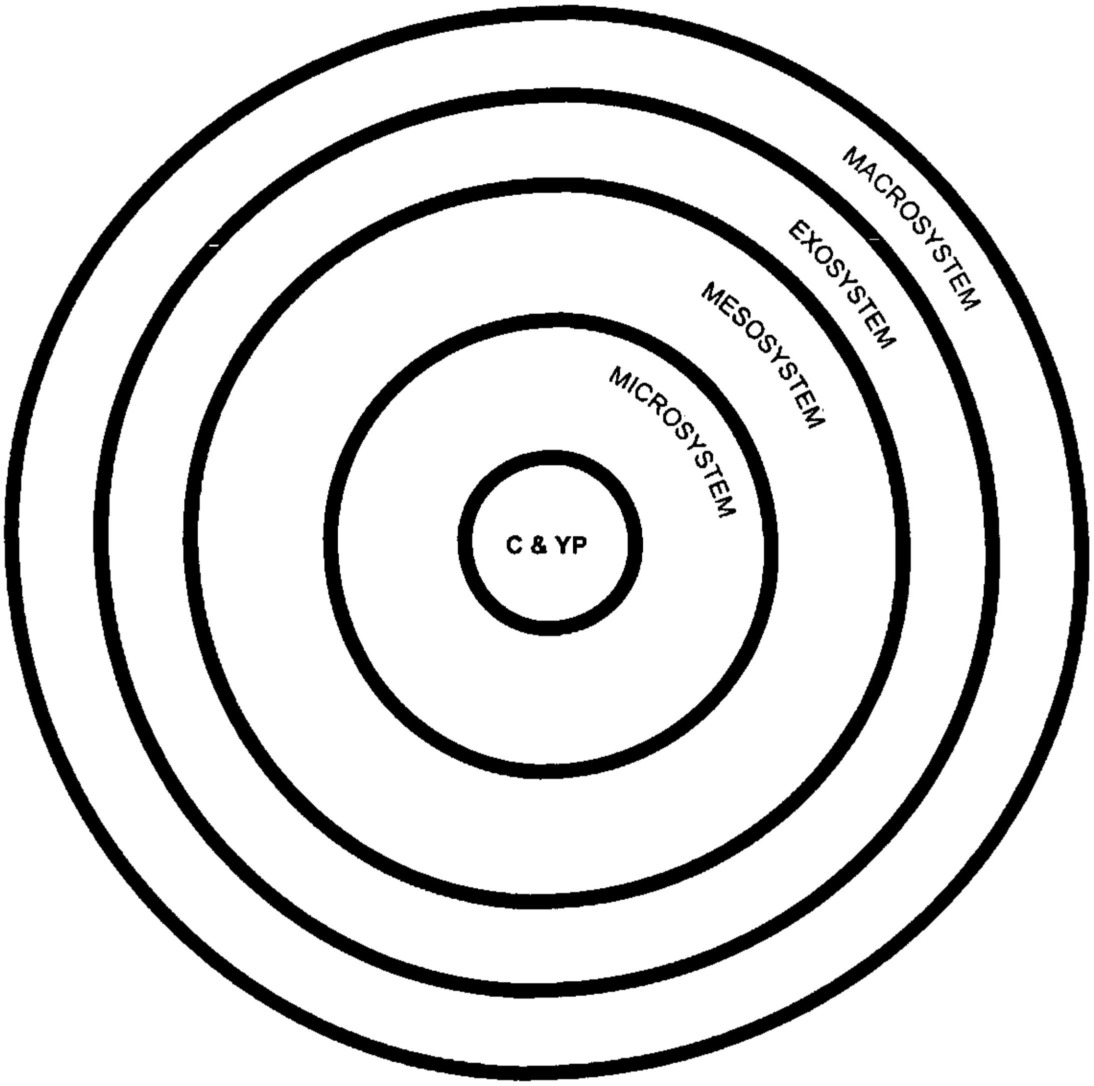

Figure 2.1 Bronfenbrenner's socio-ecological approach

The first layer is termed the microsystem. This is the layer closest to the child and contains the structures with which the child has most contact, encompassing the relationships and interactions a child has with his immediate surroundings. At this level relationships have impact in two directions, both away from and towards the child. These have been termed bi-directional influences (Bronfenbrenner 1990) and occur amongst all layers. At this level however, these bi-directional influences are strongest and have the greatest impact on the child. The next layer, the mesosystem, consists of the interrelations between the microsystem, or connections between the contexts in which the child participates. This is followed by the exosystem which defines the settings or contexts in which the child does not play a direct part but in which significant decisions are made affecting those individuals who do interact directly with the child. The outermost layer is termed the macrosystem. This consists of the belief systems and ideology of society and includes the overarching patterns of politics, values, attitudes and ideologies of a culture. Within this approach Bronfenbrenner acknowledges that the effects of the larger principles within the macrosystem have a cascading influence through the other layers, in turn affecting the structures in which people function. These affects ripple towards the child within the context of their microsystem. Thus this approach acknowledges the interaction of the larger environment on children's experiences, both directly and indirectly, whilst recognising the agency of children in their influence upon their environments as well as being influenced by those around them (Greene and Hogan 2006). Lastly the chronosystem encompasses the dimension of time alongside the patterning of events and transitions over life. These can be imposed externally or arise from the child. Bronfenbrenner believes that these new changes affect a child's experiences. Berk argues that "since children select, modify and create many of their own settings and experiences ... children are both products and producers of their own development" (Berk 2000: 30). This reflects children's capacities as active social agents operating within a responsive environment.

In the next section I explore the re-conceptualisation of childhood and apply this to both children's nursing research and carrying out research with children.

Re-conceptualisation of childhood

More than two decades ago a different way of viewing children and childhood based on social constructionism and influenced by children's rights began to re-conceptualise the social status and positioning of children (James 2001, James and Prout 1997). This new paradigm called for children and young people to be recognised as social actors and for their perspectives to be heard in order to better understand their position in society (James and Prout 1990). This re-conceptualisation of childhood depicts children as having their own voice, recognises that children are not passive receptors of socialisation but are active social agents managing their own experiences and negotiating around adult controls (Jackson and Scott 2000, Buckingham 1994) with the potential to be active agents to the situations and events in their lives and not merely passive to them.

Thus within this approach children are seen as being actively involved in the construction of their own social lives and the lives around them (James and Prout 1997) with different experiences and knowledge to adults. In research terms, "contemporary thinking frames children as having the potential to be active participants in research, with their own agency and voice" (Carter 2009: 3), no longer viewing them as passive objects of research but instead as social agents (Kirk 2007). A clear expectation now exists to elicit the voices of children themselves (Runeson et al 2001).

The re-conceptualisation of childhood is now reflected within health care policy. An expectation now exists of more meaningful participation, involvement and attempts to see the experiences of children through their own eyes across a range of children's services (Coyne 2006). Incorporated within this is a growing recognition of children's rights (United Nations Convention on the Rights of the Child 1989) and the need to consult, listen to and respond to children (see Children's National Service Framework, Department of Health 2004, Children Act 1989). Thus, consultation with children and young people has now become a key policy issue recognised and promoted by voluntary non-Governmental organisations (see for example, National Children's Bureau 2004). Since the advent of the Children Act in 1989, healthcare workers have been encouraged to listen to the views of children and young people, encouraging their involvement in discussions affecting them.

Children's rights to information and participation have also been reflected in relation to policies appertaining to children in hospital (Department of Health 1997, 1991). For instance, The Welfare of Children and Young People in Hospital Report (1991: 6) recommends that:

> "Young people should be kept as fully informed as possible about their condition and treatment to enable them to exercise their rights. Even where younger children do not have the required understanding they should be provided with as much information as possible and their wishes ascertained and taken into account".

Similarly, in 2002 the Department of Health again underlined its commitment to involving children in all aspects of its work in its paper "Listening, Hearing and Responding. Department of Health Action Plan: Core Principles for the Involvement of Children and Young People". This was followed by the Children's National Standards Framework (Department of Health 2004), a ten year strategy which states that hospital services should be child centred with children being consulted and involved in all aspects of their care. For example:

> "Children and young people should receive care that is integrated and co-ordinated around their particular needs, and the needs of their family. They, and their parents, should be treated with respect, and should be given support and information to enable them to understand and cope with illness or injury, and the treatment needed" (Department of Health 2004: 9).

More recently in 2009, the Department of Health reaffirmed its commitment to the provision of services that are patient centred, although children and young people themselves were not specifically mentioned:

> "NHS services must reflect the needs and preferences of patients, their families and their carers" (2009: 3).

Within healthcare the re-conceptualisation of childhood is reflected in that whilst children's nurses recognise that children may be marginalised in society, they aim to practice in a way that focuses on children's strengths and agency. This translates into attempting to understand what it is like for children and young people being in hospital and aiming to "deliver a health service that meets real rather than perceived needs" (Gibson and Twycross 2008: 3081), incorporating learning what children understand about their illness and treatment, the nursing care they receive and what it is like being in hospital from their own perspective (Carter, Marshall and Sanders 2009).

Integral to the re-conceptualisation of childhood is that accounts must elicit children's and young people's own perspectives and not the viewpoints of adults. If health care professionals are to begin to understand children's worlds and provide child centred, high quality care (Kortesluoma, Hentinen and Nikkonen 2003), the accounts of children themselves must be sought. Children's nurses also now acknowledge the need to recognise the diversity of children's lives and childhoods across age, illness, gender and disability. Children and young people are no longer viewed as "other", but instead recognise that children are the experts in their own lives and experiences (Carter 2009).

In research terms, accessing this expertise translates into using the appropriate methods. Participatory research has an underlying philosophy that those being researched are empowered to truly participate in order to have their voices heard (Gibson et al 2005). In comparison to traditional and psychological approaches to childhood research which have tended to objectify children, participatory methods are emancipatory, allowing researchers to access the authentic perspectives of the children being researched. An assumption that children cannot engage fully in research without aid from adult designed participatory methods reinforces the traditional model of children as incompetent and incomplete. Ethnographic research instead requires a move away from adult centred understanding of a phenomena and seeks to understand the ways in which children's social worlds are shaped and controlled by them (Emond 2006). Gallacher and Gallagher (2005) suggest that it is within the framework of ethnography that participatory methods have most to offer having the potential to "unfold children's everyday experiences by listening to their many voices" (2005: 3), thus acknowledging the diversity and multiplicity of childhoods and "resisting a totalising interpretation that claims to be a singular, "accurate" version of children's lives" (Blumenreich 2004: 80). It also means to undertake research reflexively, acknowledging our position as adult researchers and taking care not to impose adult viewpoints and interpretations onto children's accounts:

> "So I see that the basic question is not between adults and children but rather between different cultures which I see are always somehow present when doing research. What affects the interpretations of data is that it is always researchers who do the interpretation-work. It is an adult-interpretation as far as researchers are adults. What a researcher can do is to take the context into account and try to make visible the different cultures and in this case try to reach children's worlds. In any case I see that an effort to reach some kind of authentic world of children is impossible. Instead different versions of children's worlds can be found in different contexts" (Ritala-Koskinen 1994: 313-314).

As Sartain, Clarke and Heyman (2000) comment, parents themselves may also reinforce the view that children are incompetent or passive by "de-legitimising" the narratives of their child. Instead, researching with children offers opportunities in creating oppositional pictures of children, drawing upon their strengths and agency and subverting dominant discourses (Blumenreich 2004).

However, despite standards and policies outlining that children in hospital should be actively involved in decisions around their care, Coyne (2006) comments that whilst there is a growing recognition within children's nursing of the importance of consulting with children and obtaining their views, this is not always reflected within healthcare where children's views are rarely sought in the development of policies (Bricher 2000). Furthermore, Payne (2009) highlights that despite the explosion in policies relating to children and young people over the last 10 years reaching into every aspect of a child's life in the UK, much of it has been focused on structural change and in the main have been service-orientated and adult-led. For instance, Rabibee, Sloper and Beresford (2005) comment that despite the emphasis in policy on the participation of disabled children and young people, participation has been through other agents rather than being direct. As a result, knowledge of their experiences is largely second hand knowledge given by adults whose views may differ from those of the children.

Criticism has also been levelled towards many of the policies in place promoting children's consultation and involvement. For example, it has been argued that The Children's Charter (The Patient's Charter: Services for Children and Young People, Department of Health 1996) continued to reflect the common belief that children's and young people's perspectives may be represented by their parents or other adult members of society, thus perpetuating their dependency on adults (Glasper and Powell 1996). This stance appears to continue within the National Standards Framework which states that "parents are usually the experts on their child", thus failing to acknowledge children's own capacities and abilities in being the experts on themselves (2004: 16). Along similar lines, The United Nations Convention on the Rights of the Child (1989) draws recognition to the role of parents in making decisions for children, stipulating that decisions are made on the basis of the child's best interest. However, as Lansdown (1994) argues, this has the potential to be used as a tool to override the wishes and feelings of children, once again reflecting adults' power over children. As James and James (2008) comment, decisions made by adults in the best interest of the child must be understood not only as an expression of concern for children's needs but also in terms of futurity; as an investment in their future as adults. Furthermore, as Lansdown (2000) suggests, due to children's lack of civil status, they themselves have no means of ensuring that their interests are heard. Indeed, without a principled legislative framework to back it up, there is no guarantee that their interests will be considered or that there will be any means of redress in the event of a failure to do so. Secondly he argues, the operation of a best interest principle may not be beneficial to children:

> "It can be, on the contrary, a powerful tool in the hands of adults, which can be used to justify any of their actions and to overrule the wishes and feelings of children. It is extremely difficult for any adult to determine the best interests of a child. ... Even more important, is the recognition that children have basic civil rights – the right to be listened to and taken seriously, the right to freedom of expression, the right to freedom of conscience, the right to physical integrity. If one accepts these principles as given, then they form the principled framework against which the concept of best interests can be tested. Without it, the rights of the child can be subjugated to personal prejudice, an unwillingness to resolve conflict, lack of any consideration of the child's perspective or simply a battle for power in which the adult is invariably the stronger" (Lansdown 2000: 41).

Although notions about the innocence of children have its roots within Western tradition, James and James (2008) argue that it is becoming central to the global construction of childhood that the United Nations Convention on the Rights of the Child (1989), for instance, is helping to forge. For example, the Convention rests upon a universal and undifferentiated model of childhood. Children "are conceptually categorised together in the context of their collective vulnerability … as if their needs and best interest can be articulated with one largely undifferentiated voice, irrespective of class or culture" (James and James 2008: 30). Meanwhile, Berman (2003) comments that the United Nations Convention on the Rights of the Child contains a set of moral assumptions about what is good or bad for a child, conceptualising children as innocent and passive creatures upon whom society impacts in some form, thus depicting a flawed and misleading picture of children.

The recognition that research needs to be carried out with children rather than on them has led to the emergence of guidelines (see for example, Medical Research Council 2004, National Children's Bureau 2003, Royal College of Paediatrics and Child Health Ethics Advisory Committee 2000). However, whilst these acknowledge the new re-conceptualisation of childhood through their acknowledgement of the need to include children within research, these tend to reflect discourses of children's vulnerability and need for protection, resonating with those above in relation to policies. For example, "Guidelines for the ethical conduct of medical research involving children" (Royal College of Paediatrics and Child Health: Ethics Advisory Committee 2000: 177) states that "many children are vulnerable, easily bewildered and frightened, and unable to express their needs or defend their interests". Similarly, "Research Ethics, The Royal College of Nursing Guidance for Nurses" (RCN 2009: 6) refers to children as "people who are vulnerable", although the guidance does acknowledge the importance of including vulnerable populations in research in order to ensure that they are not disadvantaged due to their views and experiences not being represented. This protective stance is also taken by the Medical Research Council (2004) in their document "MRC Ethics Guide: Medical Research involving Children" (see appendix 1 and also Carter, in press). However, despite this these offer clear guidelines for researchers working alongside children and young people in terms of assent and dissent and the ways in which children and young people should be approached and engaged within research, and are central documents alongside other position statements and guidance (see Twycross, Gibson and Coad 2008, Gibson and Twycross 2007) in relation to carrying out research with children and young people. These will be expanded upon in Chapter 4.

In part one I have explored Western conceptualisations of childhood as espoused by sociology, developmental psychology and socio-ecology, following this with an exploration of the re-conceptualisation of childhood. In the next part I outline the literature around children's experiences of hospitalisation.

Children's and young people's experiences of hospitalisation

Introduction

In this section I review the literature in relation to children's and young people's experiences of being in hospital, being ill and undergoing treatment and perceptions of care. Table 2.1 provides a critical summary of the literature (in chronological order). For each study included, the table addresses the ages of the participants, the setting in which the research was conducted, the methods used, the key findings and the study limitations. The table is sub-divided into three sections which focus on (1) experiences of being in hospital, (2) experiences of being ill and undergoing treatment, and (3) experiences of care and children's nurses. At the end of each of these sections, a short summary of the overall findings from across the reviewed studies is presented.

The material presented in table 2.1 is now further explored and critically considered providing a more detailed elaboration of the synthesis table.

Table 2.1 Summary of literature (1999-2009) relating to children's and young people's experiences of being in hospital, being ill and undergoing treatment and experiences of care and children's nurses

Authors	Sample	Setting	Methods/ activities	Key findings	Limitations
Section 1: Experiences of being in hospital					
Polkki, Pietila and Rissanen (1999)	20 children aged between 7-11 years.	Children's wards of a University hospital in Finland.	Writing around experiences of pain whilst in hospital and interviews focusing upon these.	Children able to describe their pain experiences as physiological and psychological and the methods which helped to relieve their pain.	Carried out in Finland which may limit its applicability to a UK setting. Specific to children.
Noyes (2000)	18 children/young people aged from 6-18 years, dependent on ventilation.	Home, school and other settings in UK.	Talk and draw, play techniques and focused interviews.	Restricted access to information and only limited input into decision making revealed. Vivid, mainly negative, lasting memories of being in hospital.	Specific to children/young people dependent on technology.
Sartain et al (2001)	11 children aged between 5-12 years, with acute illness, alongside 40 families.	Large district general hospital and paediatric hospital at home service in UK.	Semi-structured interviews and drawing.	Seven children stated a clear preference for hospital at home.	Specific to children with acute illness. Specific to children.
Horstman and Bradding (2002)	99 children; 50 aged between 6-10 years with chronic illness, predominantly cancer and 49 healthy children to act as comparison.	Four hospitals (type not specified) and healthy children from three primary schools in UK.	Draw and write technique, short semi-structured interviews.	Children with chronic illness revealed missing family and friends when in hospital. A need for information regarding their treatment, diagnosis and prognosis cited.	Specific to children with cancer/chronic illness in relation to hospital experience. Specific to children.
Carney et al (2003)	213 children/young people aged between 4-17 years.	Children's wards of two district general hospitals in UK.	Verbal structured questionnaire consisting of five questions related to hospital stay. Verbal unstructured questionnaire (story/poem about hospital experience). Visual structured questionnaire (speech inserted into bubbles on five drawings related to hospital stay). Visual unstructured questionnaire (drawings about being in hospital).	Different aspects of being in hospital are important to different age groups. Verbal structured questionnaire most effective at obtaining children's/young people's views. Visual structured questionnaire able to identify sequence of feelings experienced by children/young people.	Questionnaire approach limits children's/young people's responses.
Gibson et al (2005)	38 children/young people aged between 4-19 years, either receiving or having had undergone treatment for cancer.	Three paediatric oncology settings in the UK.	Creative, age-appropriate techniques including play, puppets, draw and write techniques, interviews, activity day and questioning.	Children did not like the things that made hospital different to home. Play is an important feature of hospital life. Many of the older children felt that they required more information about their illness and treatment. Support provided by family, friends and hospital staff is important. The ways in which treatment affected children/young people.	Specific to children/young people with cancer.
Kortesluoma and Nikkonen (2006)	44 children aged between 4-11 years.	Four children's wards in a University hospital in Finland.	Interviews.	Children are able to communicate their pain experiences competently.	Carried out in Finland which may limit its applicability to a UK setting. Specific to children.
Lindeke and Johnson (2006)	120 children/young people aged between 4-20 years.	Large USA metropolitan hospital (type of hospital not specified).	Brief survey including three open-ended questions around best and worst things about being in hospital and changes that could be made.	Pain and discomfort were cited as worst aspects of being in hospital. Play activities and positive relationships with staff valued. Different aspects important to different age groups.	Carried out in USA which may limit its applicability to a UK setting.

Authors	Sample	Setting	Methods/ activities	Key findings	Limitations
Clift, Dampier and Timmons (2007)	6 young people aged between 11-15 years.	Two children's wards (orthopaedic and general surgical) in a large UK University hospital.	Semi-structured interviews.	Young people identified experiencing anxiety around admission to hospital, having a degree of participation in care, difficulties with sleeping, the importance of peer support, positive relationships with health care professionals and limited provision for adolescents in the ward settings.	Specific to older children and young people.

Summary: Different aspects of being in hospital are important to different age groups; children and young people in hospital have limited access to information and opportunities to be involved in decision making and the presence of family and friends and positive relationships with staff are important. Research to date is fragmented into specific groups of children and young people around ages and acute or chronic illness, failing to provide equity in terms of engagement and participation.

Section 2: Experiences of being ill and undergoing treatment

Authors	Sample	Setting	Methods/ activities	Key findings	Limitations
Horne (1999)	2 young males on long term ventilation.	Not identified.	Taped conversations, stories, drawings and observation of interactions.	"I don't have any freedom". "It's not being ventilated that's the problem, it's being disabled". "People take advantage". "It is difficult to breathe at times". "It's alright really".	Specific to young people dependent on technology. Specific to young people.
Rydstrom, Dalheim Englund and Sandman (1999)	14 children/young people aged between 6-16 years, with moderate or severe asthma.	Hospital in south of Sweden.	Interviews.	Children and young people described feeling that they both participate in everyday life but also feel like outsiders.	Carried out in Sweden which may limit its applicability to a UK setting. Specific to children/young people with asthma.
Sartain, Clarke and Heyman (2000)	7 children/young people aged between 8-14 years, with chronic illness.	Three Trusts in UK providing both secondary care and primary care for children through either community children's nurses or outreach specialist nurses.	Semi-structured interviews and drawing.	Children and young people are competent interpreters of their world. Children and young people with a chronic illness cannot be treated as a homogenous group.	Specific to children/young people with chronic illness.
Atkin and Ahmad (2001)	51 children/young people aged between 10-19 years, (26 with sickle cell disease, 25 with thalassaemia).	Midlands and northern England.	Interviews.	Children and young people described coping with chronic illness, coping with uncertainty and coping with the responses of others.	Specific to older children/young people with sickle cell disease or thalassaemia.
Carter, Lambrenos and Thursfield (2002)	Young people aged between 13-19 years, with chronic pain.	Child and Family Services Centre. Receiving treatment at a specialist children's hospital in UK.	Pain workshop consisting of guided activities, focus group, post-it pyramids and peer interviews.	"No one's pain's the same, it's always there", "getting on with it", "it's hard 'cos … but we're keeping with the dream" and "it depends … some are OK".	Specific to young people with chronic pain. Specific to young people.
Wise (2002)	9 children/young people aged between 7-15 years, at least one year post liver transplantation.	In home setting/out patient department of USA hospital (type not specified).	In-depth conversations and drawing.	Children and young people described "being the same and different", what was ordinary and extraordinary about their experiences in hospital, being in pain and out of control with their lives and their parents' responses to their liver disease.	Carried out in USA which may limit its applicability to a UK setting. Specific to children/young people post liver transplantation.
Eklund and Sivberg (2003)	13 young people aged between 13-19 years, with epilepsy.	Paediatric department of University hospital in southern Sweden.	Semi structured interviews.	Young people described the "experience of strains" including seizures, side effects of medications and feeling different and the coping strategies they adopted.	Carried out in Sweden which may limit its applicability to a UK setting. Specific to young people with epilepsy. Specific to young people.

Authors	**Sample**	**Setting**	**Methods/ activities**	**Key findings**	**Limitations**
Garth and Aroni (2003)	4 children aged between 6-12 years, with cerebral palsy, alongside 6 mothers.	Specialist school in Australia.	In depth semi-structured interviews, vocalisation and body language.	Children wished to be included in medical consultations and felt that inclusion was important.	Carried out in Australia which may limit its applicability to a UK setting. Specific to children with cerebral palsy. Specific to children.
While and Mullen (2004)	11 young people aged between 12-16 years, with sickle cell disease or thalassaemia approaching transition to adult services.	Community based sickle cell and thalassaemia centre in UK.	Semi-structured questionnaires.	Young people reported that sickle cell disease "interfered" with various aspects of their lives with fatigue and pain being experienced commonly.	Specific to young people with sickle cell disease or thalassaemia. Specific to young people. Specific to those approaching transition.
Forsner, Jansson and Sorlie (2005a)	7 children aged between 7-10 years, with a short term illness.	In home or hospital setting, within six months of being discharged from a paediatric ward in a hospital in northern Sweden.	Interviews.	The children combined reality and imagination when narrating their experiences of being ill, telling of contrasting experiences; "scared/confident", "sad/cosy", "hurt/having fun" and "being caught and trying to escape".	Carried out in Sweden which may limit its applicability to a UK setting. Specific to children with a short term illness.
Forsner, Jansson and Sorlie (2005b)	5 young people aged between 11-18 years, with a short term illness.	In home or hospital setting, within six months of being discharged from a paediatric ward in a hospital in northern Sweden.	Interviews.	The young people described being ill as being lost, hurt and in need of comfort from both themselves and others.	Carried out in Sweden which may limit its applicability to a UK setting. Specific to older children and young people with a short term illness.
Coyne (2006)	11 children/young people aged between 7-14 years, alongside 10 parents and 12 nurses.	Four paediatric wards in two hospitals in England.	In depth interviews, observation and questionnaires.	Children expressed the need for consultation and information although they had varying experiences of being consulted about their care and treatment.	Specific to children above 7 years.
Earle et al (2006)	5 children/young people aged between 4 to 17 years, dependent on ventilation.	Out patient clinics, hospital, home setting and school in Canada.	Semi-structured interviews.	"It's okay, it helps me breathe". The medicalisation of childhood. Being a child. Hopes for the future.	Carried out in Canada which may limit its applicability to a UK setting. Specific to children/young people dependent on technology.
Rhee, Wenzel and Stevens (2007)	19 young people aged between 12-18 years, with asthma.	Central Virginia, USA.	Focus group.	Young people outlined the emotional reactions to living with asthma, the perceptions and attitudes of others and their coping strategies.	Carried out in USA which may limit its applicability to a UK setting. Specific to young people with asthma. Specific to young people.
Lindsay Waters (2008)	13 children/young people aged between 5-16 years, with renal disease. 14 carers and 36 staff members also participated.	Children's renal unit. Location not identified.	Participant observation, interviews and drawing.	Children and young people revealed the physical and social impact of renal treatment, highlighting management of their disease, inhabiting a "renal geographical space" and "renal body" and a "renal social world".	Specific to children/young people with renal disease.
Summary: Research to date reveals children's and young people's perceptions of both living and coping with chronic illness, the physical and social impact of treatment and a desire for consultation and inclusion. The literature separates children and young people into disease groups, failing to explore illness experiences as a whole.					

Section 3: Experiences of care and children's nurses

Authors	**Sample**	**Setting**	**Methods/ activities**	**Key findings**	**Limitations**
Holyoake (1999)	35 young people aged between 13-17 years, with mental health issues.	Regional adolescent mental health unit in UK.	Questionnaire and discussion.	Doctors (and possibly psychologists) make important decisions. Nurses perceived as being "all rounders" with no particular authority.	Specific to young people with mental health issues. Specific to young people.
Pelander and Leino-Kilpi (2004)	40 children (20 aged 4-6 years and 20 aged 7-11 years). 20 children with insulin dependent diabetes mellitus; the other children having been treated on the children's surgical ward.	Home setting or outpatient clinic of paediatric department of a University hospital in Finland.	Interviews and stories.	Children expected nurses to be nice, kind and friendly, trustworthy and have a sense of humour. Children wished for nurses to provide entertainment, educational and caring activities.	Carried out in Finland which may limit its applicability to a UK setting. Specific to children.
Carter (2005)	5 families (10 children with complex health care needs and their siblings, aged between 2-13 years).	Children and siblings accessing a Diana Team in UK.	Participant observation, peer interviews, photographs, scrapbooks, poems, stories, drawings and other materials.	Children indicated the technical competence and skills they felt were important to providing care. Children wished for nurses who were "kind" and "fun". Children believed that the Diana Team had made a difference to themselves and their parents.	Limited to applicability beyond Diana team.
Schmidt et al (2007)	65 hospitalised children/young people aged between 5-18 years.	Children's hospital in USA.	Semi structured interviews, questionnaires and written methods.	Children and young people appreciated nurses who had a positive attitude and effect, provided physical comfort and entertainment, acted as advocates, provided basic needs, treated them as individuals and provided reassurance.	Carried out in USA which may limit its applicability to a UK setting.
Randall, Brook and Stammers (2008)	10 hospitalised children. Ages not specified.	Children's hospital in UK.	Semi structured interviews with body outlines.	Whilst children's nurses have some innate qualities they also require education to enable them to nurse children. Children identified three areas of learning to help make a good children's nurse; attitudinal and professional persona, cognitive and psychomotor learning and experiential learning.	Specific to children.
Moules (2009)	9 young people (aged 12-16 years) acting as researchers, collecting data from an additional 129 children and young people aged between 9-14 years.	Colleges and primary schools in UK.	Vignette around the experience of a young person in hospital.	Children and young people believed that having technical expertise, providing explanations and choice, being treated with respect and staff being friendly were characteristic of quality hospital care.	Specific to children above 9 years.

Summary: The important attributes children and young people believe children's nurses should have indicated. Technical expertise and competence are paramount. Research to date relates to specific setting such as mental health or community setting or to particular age groups.

Experiences of being in hospital

Despite there being a wealth of literature on families' experiences of being in hospital, comparatively little has been written about children's perceptions of being a patient in hospital (Battrick and Glasper 2004). Carney et al (2003) argue that traditionally parents and professionals have been used as proxies in attempts to learn how children experience being in hospital. However, it has been recognised that there can be discrepancies between the views of children and those of adults (see Beresford 1997) leading to differences between what children and adults feel is important (Garth and Aroni 2003). For example, work by Hinds et al (1999) into the experience of fatigue in children with cancer as described by children, adolescents, parents and staff found some noticeable differences alongside shared similarities.

Studies that have attempted to elicit the views of children and young people have tended to concentrate upon specific populations (for example, the experiences of critically ill children (see Carnevale 1997), children and young people who are dependent on technology or those with either acute or chronic illnesses). Other studies meanwhile have used methods such as semi-structured questionnaires (Kari et al 1999, Fleitas 1997) and visual structured questionnaires (Carney et al 2003) which arguably limit children's and young people's responses and inhibit their opportunities to describe what is important to them. Furthermore, research to date is fragmented into specific groups of children and young people around ages and acute or chronic illness. Thus whilst some excellent studies have been carried out with children and young people, the body of literature as a whole is patchy.

More recently a number of studies have focused directly upon children's views of hospitalisation using child-oriented approaches in order to elicit children's own perceptions. One UK study undertaken by Carney et al (2003) explored the perceptions of 213 school aged children from the children's wards of two district general hospitals in order to investigate a broad range of experiences in a general population of children and continue the development of a child-centred paediatric service. The children completed one of four questionnaire types; verbal structured and unstructured and visual structured and unstructured. The findings revealed nine categories; organisation of events, environment, procedures, interaction with staff, emotions, perception of hospital, information, separation from home life and describing pictures. The authors concluded that different aspects of hospitalisation are important to different age groups with adolescents finding the physical environment of hospital most important, indicating the importance for appropriate adolescent facilities. Interestingly, the study revealed that the verbal structured questionnaire was most efficient at obtaining children's views with the visual structured questionnaire being the only method to recognise children's sequence of feelings before, during and after hospitalisation. The authors suggested that children should be prepared prior to hospital admission in order to reduce initial anxiety and negative perceptions with future follow up work into children's lasting perceptions of being in hospital to help generate a greater understanding of children's views.

Similarly, work by Sartain et al (2001) involved a comparison of forty families', including eleven 5-12 year olds, experiences of hospital and hospital at home. The children in the hospital group described enjoying the hospital facilities including the playroom, hospital school, the ward computer and the food, being able to make friends, positive relationships with the nurses and having visitors. Negative factors included boredom, being woken up by the nurses and the administration of medicines. The study revealed that seven children had a preference for home care attributed, by the authors, to the relative normality of their experience.

Qualitative work carried out by Lindeke and Johnson (2006) explored the views of 120 children and young people about their perceptions of quality in their hospital experiences. This study is included within this review as the children focused upon their experiences of care. The 19 younger children (aged 4-6 years) revealed that the best things about being in hospital were related to play activities, the care provided and the presence of parents and families. The worst parts; being in pain and discomfort, mainly related to treatments. For the 39 children aged between 7-11 years, the best things were related to play activities and equipment, healthcare staff and the care provided, and food. The worst things were revealed as being in pain and discomfort, undergoing treatments, food, their illness, being in hospital, trying to sleep and confusing communication. The 62 young people (aged 12-20 years) who participated appreciated staff, the care and treatment, the facilities and equipment, recreational activities, the food and the presence of family. This group appreciated staff listening to them and staff who were "nice, familiar, fun, positive, prompt and experienced". The worst things were identified as pain and discomfort, food, dissatisfaction with care, inefficient systems, being away from home, boredom and "bad communication". However, this study was conducted in the USA and this may limit its applicability to a UK setting.

Other work has focused upon experiences of being in hospital from the perspectives of particular groups of children and young people, determined by age and illnesses. Using a range of age appropriate research techniques, Gibson et al (2005) carried out a study into the experiences of 38 children and young people aged 4-19 years with cancer about their care and support needs during and after treatment. Whilst this work focused upon care and support needs, children and young people described their perceptions also of the hospital setting. This included disliking hospital due to it being different to home, particularly in relation to missing parents and siblings. Children also expressed a desire for separate areas for younger and older children, choices around bed spaces on the ward and a dislike for hospital food. Interestingly the study revealed the differences across age groups in children's and young people's experiences. Whilst young people preferred to amuse themselves when feeling unwell, children demonstrated a wish for the availability of age appropriate toys and activities. In terms of illness and treatment, younger children spoke little about being ill and having treatment. Some of the older children expressed concern about the present and the future due to having cancer, being worried about needles, having treatment and waiting to see the doctor and whether they would get better. However, young people tended to view treatment as necessary and something that needed to be got through. Whilst young children believed that they gained information about their illness and treatment from their parents rather than hospital staff, older children wished to be given information directly by hospital staff with many feeling that they were not given adequate information. However, young people did feel, in the main, that they had been given information directly from medical staff.

Earlier qualitative work by Horstman and Bradding (2002) focused upon the perceptions of 50 children aged between 6-10 years with chronic illness, mainly cancer, revealing feelings of sadness around being in hospital due to missing family and friends. Children also described the limitations that their illness placed upon their lives. Children demonstrated a need for doctors to speak with them and give information regarding their prognosis, diagnosis and treatment and described a desire to build up relationships with nursing staff.

A phenomenological study carried out by Noyes (2000) explored the views and experiences of 18 "ventilator dependent" children and young people aged 6-18 years, with regards to their care in hospital through face to face interviews. Many of the children and young people had spent significant periods of time in hospital due to their need for ventilation and this was reflected within their experiences. Children and young people revealed being deprived of an adequate education whilst they were in hospital, limited access to play provision and facilities, limited opportunities to leave the hospital setting and meet friends, restricted access to information and limited participation in decision making, isolation and vivid lasting memories of being in hospital that were generally negative. A highly significant factor was that overwhelmingly the children and young people felt that they had no voice due to their overall exclusion from decision making and information.

Work by Clift, Dampier and Timmons (2007) directly explored the perspectives of adolescents. This study examined six adolescents' experiences of emergency admissions to children's orthopaedic or surgical wards using semi-structured interviews. This study highlighted six themes; feelings of anxiety and distress surrounding admission to hospital, a degree of participation in care, difficulties in sleeping, the importance of peer support and interaction, a need for parental involvement despite the young people describing having positive relationships with the nurses and limited ward facilities failing to meet their needs as adolescents. The results revealed that adolescent's experiences of children's wards are overall positive although as the authors indicate, the small sample makes generalisation to other areas difficult.

Other studies meanwhile have centred around children's and young people's perceptions of pain whilst in hospital. One study by Polkki, Pietila and Rissanen (1999) asked children what caused them pain whilst they were in hospital in order to ascertain if children aged 7-11 years could be involved in the treatment of pain. In a similar vein, Kortesluoma and Nikkonen (2006) explored the pain experiences of 44 hospitalised children aged between 4-11 years revealing that children were able to specify the nature of pain using paraphrases and metaphors to describe it and revealing its multi-dimensionality and purpose. These authors suggest that a great amount of what we know about children's pain experiences has been sought from adults instead of children themselves and yet the study revealed the children to be competent interpreters of their own pain experiences.

In the next section I review the literature around experiences of being ill and undergoing treatment.

Experiences of being ill and undergoing treatment

Docherty and Sandelowski (1999) comment that children's illness experiences have been investigated traditionally through the eyes of adults, most often from parents and professionals, once again reflecting the belief that children's perspectives can best be elicited from adults. And yet work by Lumeng et al (2001) suggests that the perceptions of children who are ventilator dependent differ from those of their parents. It has been argued that illness can have different meanings for professionals and patients (Forsner, Jansson and Sorlie 2005a) with patients holding subjective, emotional knowledge and professionals basing their knowledge around objective symptoms. Where children's and young people's perspectives of illness have been explored this has been only to a limited extent, focusing largely upon long term illness (Forsner, Jansson and Sorlie 2005b) and separating children and young people into disease groups, thus failing to explore illness experiences as a whole. Gibson et al (2005) comment that alongside a scarcity of research into children's experiences of cancer services, those that do exist (prior to Gibson et al's own study) have tended to elicit the views of older children and young people thus precluding the important perceptions of younger children. Further weaknesses exist in that the body of knowledge that was available when I commenced the study has tended to focus upon the experiences of specific groups of children and young people, such as those with particular illnesses or dependent upon technology.

Increasingly however, there has been a growing interest in children's perspectives of illness with papers in existence describing issues arising from carrying out research with children and appropriate paradigms to take into this important area (see Woodgate 2001, Miller 2000). Work by Forsner, Jansson and Sorlie (2005a) illuminated the experiences of seven children aged 7-10 years, and five young people aged between 11 -18 years (Forsner, Jansson and Sorlie 2005b) with short term illness. Their work revealed that children combined reality and imagination with contrasts co-existing including being "scared/confident", "sad/cosy" and "hurt/having fun". Importantly, children described feeling caught by the illness and trying to escape from it. Young people meanwhile, described illness as disrupting their daily lives and making things unrecognisable; the authors concluding that being ill for this age group implied being lost, hurt and in need of comfort.

Other studies have been carried out in order to elicit the perceptions of children and young people around having a specific illness. For example, Rydstrom, Dalheim Englund and Sandman (1999) illuminated the experiences of 14 children, aged between 6-16 years, with asthma using a phenomenological hermeneutic approach. The authors concluded that children strived to live normal lives although at times they felt like participants in everyday life and at other times like outsiders. As participants they felt confident in their own knowledge, in other people's desire to help and that their medications would work. As outsiders however, they felt deprived, guilty, lonely, anxious and afraid.

Themes around normality were reflected within work by While and Mullen (2004) in their exploration of the lived experience of 11 young people aged 12-16 years with sickle cell disease as they transferred to adult services. This revealed that sickle cell disease interfered with aspects of their "normal" lives with fatigue and pain being common symptoms. The authors concluded that the medical mode of service delivery may not meet all their needs.

Work by Sartain, Clarke and Heyman (2000) explored seven children and young people's experiences of having a chronic illness using semi-structured interviews and drawing. These authors concluded that children and young people with a chronic illness are competent interpreters of their world but cannot be treated as a homogenous group. A number of other studies have been conducted into the perspectives of adolescents with a range of mainly chronic illnesses. For example, a study by Atkin and Ahmad (2001) with 51 children and young people with thalassaemia or sickle cell disease focused upon experiences of coping with a chronic illness, the uncertainty of their illness and the responses of others towards them. The focus upon coping was reflected again in work by Rhee, Wenzel and Stevens (2007) whose exploration into the psychosocial experiences of 19 young people living with asthma included general perceptions, emotional reactions to living with asthma, the perceptions and attitudes of others and coping strategies. The findings of these studies resonate with work by Eklund and Sivberg (2003) who investigated 13 adolescents lived experience of epilepsy describing the "experiences of strains" including seizures, side effects of medications, limitations of activities, feelings of being different and coping strategies including finding support and being in control.

Other studies have examined children's and young people's everyday lived experiences of having an illness. A phenomenological study into the lived experience of nine children and young people aged 7-15 years undergoing liver transplantation carried out by Wise (2002) identified the following themes; "being the same and different" in which children and young people described their experiences with peers before and after the transplant alongside their experiences of connecting to the donor; the disruption of being in hospital due to the many people children do not know and the strangeness and unpredictability of hospital, routines, experiences around pain and being hurt including those around procedural pain and their parents' responses to their illness and children's concern for them. Similarly, work by Lindsay Waters (2008) explored 13 children's and young people's experiences of long-term renal illness, alongside 14 parents/carers and 36 staff members, through children's stories and drawings, documentary analysis and interviews. The author described children living and growing up in a renal space as a result of living with and managing long-term renal illness, alluding this to living in a renal body and inhabiting a renal space (the haemodialysis unit), revealing children's everyday experience of their long-term illness.

Other work has also been carried out in order to elicit the perceptions of children and young people who are dependent upon technology. A Canadian study carried out by Earle et al (2006) explored five technology dependent children's and young people's experiences of home ventilation through a case study approach. Four themes emerged; that children felt "okay" about the technology in their lives; the medicalisation of childhood with children and young people having high levels of comfort and knowledge within the technology, health professionals and the hospital setting itself; that children enjoyed being a child and having friendships and hobbies; and lastly hopes for the future with all appearing to have a positive view on life and hopes of a bright future. Similar findings emerged in a phenomenological study by Horne (1999) into the experiences of two long term ventilated adolescents. This revealed that having limited freedom, believing that their disability was more of a problem for them than the ventilation and accepting their condition and need for ventilation were the predominant issues.

Increasingly, children and young people have provided important insights into their desire for information regarding their illness and treatment and to be involved in decisions and care. Work by Coyne (2006) explored 11 children and young people's, views of participation in hospital through interviews, questionnaires and observation. Coyne described children expressing the need for consultation and information in order to understand their illness, be involved in their care and prepare themselves for procedures. However, children's experiences revealed varying experiences of being consulted about their care and treatment and that their own opinions and views were underused. Similarly, work carried out by Garth and Aroni (2003) with 4 children with cerebral palsy revealed their desire for more information about medical procedures and for medical staff to consult with them. These findings are reflected in Carter, Lambrenos and Thursfield's (2002) study which revealed that young people with chronic pain sought to be involved alongside health professionals in discussions about their pain, valuing those who listened and responded to them.

The next section reviews the literature around children's and young people's experiences of care and children's nurses.

Experiences of care and children's nurses

Randall, Brook and Stammers (2008) comment that the literature on children's views of nursing is small, dated and mainly North American (see Fleitas 1997, Bluebond Langner 1978) with few articles focusing upon children's perspectives, particularly those of children with complex needs and their siblings in relation to service provision, although Carter (2005) does address this. Traditionally, quality of nursing care has been defined and evaluated from the perspective of professionals or adult patients (Pelander and Leino-Kilpi 2004). This is reflected within children's nursing where the quality of nursing has been typically evaluated by parents rather than children using mainly parent satisfaction surveys, completed either solely by parents (Schaffer et al 2000, Homer et al 1999) or by parents and children together (Kaplan et al 2001). Other weaknesses lie in that research to date relates to specific settings such as community, particular disease groups or conditions such as mental health or to particular age groups.

A qualitative study by Pelander and Leino-Kilpi (2004) explored 20 pre-school and 20 school aged children's expectations concerning the quality of nursing care. The study revealed that expectations concerning the quality of care were related to nurses, nursing activities and the environment. Nurses were expected to be reliable, humane and have a good sense of humour with both nurses and parents expected to take part in nursing activities. Children had different expectations of the role of parents and nurses with nurses expected to provide entertainment, educational, caring and safety activities and parents to relieve fears and provide company. Interestingly, the role of other children was also emphasised as part of good care.

Similarly, work by Moules (2009) explored characteristics of quality care from the perspectives of 129 young people aged between 12-16 years using vignettes. This study revealed that children and young people believed that having technical expertise, providing explanations and choice, being treated with respect and staff being friendly were characteristic of quality hospital care.

A UK study (Carter 2005) into the views of ten children and their siblings (aged 2-13 years) experiences of a Diana community nursing service highlighted three key themes. The first; "They've got to be good with ..." related to the technical competence and skills that children expected from the Diana team in relation to providing care to the child with complex needs, with children using their parents as the benchmark of excellence. The second; "Diana nurses should (and shouldn't) be ..." revealed the important qualities and attributes that Diana nurses should and should not have, with children wishing for nurses who were "kind" and "fun" and child oriented in terms of understanding what activities were appropriate to each child and family. Importantly children highlighted that competence in children's nurses is essential but of little use if the nurse themselves does not have the qualities and attributes children wish for. Thirdly; "They've made a difference..." indicated the important difference the team had made to them and their families in terms of allowing their parents to have time for themselves away from the pressures of being a full time carer.

Work by Holyoake (1999) into the views of 35 young people aged between 13-17 years who were in-patients in a mental health unit indicated that all recognised that a hierarchy existed within the multi-disciplinary team which effected their care and treatment. Whilst nurses were seen to have "relational" power over the young people, the doctors (and possibly psychologists) were viewed as making the important decisions, with nurses generally being "all rounders" with no particular authority. This affected care and treatment in that medical staff were perceived as making the important decisions in relation to treatment whilst the nurses' role instead was as the deliverer of care. However, a large portion of the group recognised that whatever the nurses tell the doctors "affects my treatment" suggesting that nurses do have an important input into decision making.

Recent work by Randall, Brook and Stammers (2008) consulted ten hospitalised children on their views of nurses' education. This elicited children's views of those important attributes, personal qualities, skills, knowledge and experiences, of both nursing and children themselves, required by children's nurses. The children concluded that although children's nurses are special people with some qualities that are innate, they also require education to enable them to be "good" at nursing children, identifying three areas of learning that helped to make a good children's nurse which were categorised by the researchers as attitudinal and professional persona, cognitive and psychomotor learning and experiential learning. The authors propose that the children's responses may support some current educational practice and challenge other current teaching, learning and assessment strategies.

Similarly, a qualitative study by Schmidt et al (2007) explored 65 hospitalised children and young people's perceptions of nurses and nursing behaviours. This work revealed that children and young people appreciated nurses' who had a positive attitude and effect, provided physical comfort and entertainment, acted as advocates, provided basic needs, treated them as individuals and provided reassurance. However, the study was carried out in the USA which may limit its applicability to a UK setting.

In this section I have reviewed the literature around experiences of care from the perspectives of children and young people.

Summary

In Part 1 of this chapter I have explored the traditional, dominant Western conceptualisations of childhood within the realms of sociology, psychology and socio-ecology and related this to both healthcare and research with children. This was followed with an exploration of the re-conceptualisation of childhood and an application of these conceptualisations to both children's nursing practice and research with children and young people. In my search to elicit children's and young people's own unique experiences of being in hospital I sought an approach that legitimised children, positioning them centrally. To this end I was guided towards the work of Bronfenbrenner on a number of points. Firstly, the sense of the child being nested in the centre, as in Bronfenbrenner's theory, appealed to my own conceptualisation of children and young people and my aim to place their accounts centrally to the study. Secondly, Bronfenbrenner's acknowledgement of the capacities of children and young people as active social agents in shaping their own experiences reflected my own direct experiences of working alongside children and young people within the hospital setting, and was an important factor that I wished to capture within the study. Lastly, Bronfenbrenner's recognition of the ways in which the environment both affects children and young people, and yet is also affected by them, appeared to resonate with the interplay I had observed between children and young people within the ward setting. Thus the theory espoused by Bronfenbrenner gradually became increasingly important to my study and came to particularly shape my thinking about my data and findings.

In Part 2 of this chapter I have reviewed studies in relation to children's and young people's experiences of being in hospital, being ill and undergoing treatment and perceptions of care. In order to place children's and young people's views centrally I have explored the views of children and young people themselves, choosing not to incorporate the views of nurses and/or parents. The review suggests that little has been written about children's and young people's perceptions of both being a patient in hospital and being ill. Studies in which children's and young people's accounts have been elicited have focused upon specific groups, such as those with either acute or chronic illness, or those dependent upon technology. Where children's perspectives of illness have been explored, this has been only to a limited extent, focusing largely upon long term illness rather than across a range of different illness types. Similarly, the literature on children's views of nursing is small and dated with little research, particularly that carried out in the UK, focusing upon children's perspectives. Many of the studies available have tended to focus upon specific settings such as the community or on specific groups of children such as those requiring mental health care.

Traditionally parents and professionals have been used as proxies in attempts to learn how children experience being in hospital, illness and quality of nursing care. However, it is now acknowledged that there can be discrepancies between the views of children and adults. Many studies have used adult centric approaches to data collection such as semi-structured questionnaires, visual structured questionnaires or patient/parent satisfaction surveys thus limiting children's responses and inhibiting their opportunities to describe what is important to them. Other weaknesses in the body of literature lie in that the studies that have attempted to elicit the views of children have tended to concentrate upon specific groups of children and young people, such as those of a similar age range or with specific illnesses, generally chronic. Meanwhile, many have tended to elicit the views of older children and young people, thus precluding the important perceptions of younger children. Further inconsistencies exist in a definition of the starting age of adolescence with studies using a range between 11 to 13 years.

Given that the literature suggests that children and young people have not been widely engaged in research attempting to elicit their perceptions of being in hospital, the guiding question of my study was to explore children's and young people's experiences of being in hospital. In the next chapter I describe the methodology of the study, including the theoretical framework and approaches undertaken.

CHAPTER 3:
METHODOLOGY

CHAPTER 3: METHODOLOGY

> "We want to see: Professionals communicating directly with children and young people, listening to them and attempting to see the world through their eyes" (Department of Health 2004).

Introduction

In this chapter I make my case for using symbolic interactionism as the theoretical framework. My rationale for selecting a qualitative approach and justification for the use of the ethnographic approach is also presented as these were essential in answering my guiding question which was to explore children's and young people's experiences of being in hospital.

The selection of a theoretical framework

The complexities surrounding children's and young people's experiences of being in hospital were influential in my choice of the theoretical framework on which to underpin this study. Such an exploration is complicated by the multiple people and factors impacting on their experiences of hospitalisation and care, as is intrinsic to Bronfenbrenner's theory. Additionally, the ways in which both the structure and organisation of children's services (the macrosystem) might impact upon children's and young people's experiences further complicated matters.

My concern in relation to the invisibility of children and young people within the research process, particularly in the field of nursing, led to a desire to listen to the voices of children and young people themselves. Thus, through this work, I sought to provide children and young people with the opportunity to vocalise their experiences. Such a desire called for a framework which enabled the voices of the participant to be heard. Therefore, an approach which explored children's and young people's experiences of being in hospital and placed the meanings the situation had for children and young people themselves at the heart of the study held intrinsic value to me.

Symbolic interactionism

The theoretical framework chosen for this study was symbolic interactionism. Blumer (1969: 2) outlined some of the tenets of this tradition stating that:

> "... human beings act towards things on the basis of the meanings that the things have for them. The meaning of such things is derived from, or arises out of the social interaction that one has with one's fellows, and these meanings are handled in, and modified through an interpretive process used by the person in dealing with the things he encounters".

Symbolic interactionism therefore stresses the construction of meanings through interaction and suggests that these meanings influence behaviour. The interpretation of both verbal and non-verbal symbols is an important component in the establishment of meaning and the communication of expectations. Thus for the symbolic interactionist, the social world is premised upon the shared meanings of persons. As Darbyshire (1992: 40) comments, "the world in this sense has no meaning other than that which is ascribed by people and which of course is capable of being constantly refined and altered. Thus the understanding of meaning is of pivotal importance". Human interaction itself, in the words of Blumer (1969: 132), is said to represent:

> "... a vast interpretive process in which people, singly and collectively, guide themselves by defining the objects, events and situations they encounter".

The symbolic interactionist approach appeared particularly useful to the study on several counts. The aim of this interactionist investigation is to understand how participants in the social world attach meanings to events and the effect that such meanings have on their behaviour. Thus the interactionist position would not make any assumptions regarding children's and young people's experiences of being in hospital, but would seek to discover how children and young people define, understand, interpret and manage the situation. Such a framework clearly put the accounts of children and young people and their interpretations of their experiences at the centre of the study, thus enabling them to vocalise their perspectives. Along similar lines, in terms of consumerism, it appeared that symbolic interactionism was able to provide a framework that stressed the user's own criteria for evaluation, thus being cognisant of the importance of eliciting from children and young people themselves those issues that they deemed to be of significance. Importantly, the identification of past work based upon symbolic interactionism highlighted success in addressing issues of social processes, identities and shared processes (Darbyshire 1992), suggested that this framework would be well equipped to cope with the complexities likely to be raised by the study.

Recent Government papers recognise that not every child with the same condition will follow the same journey within child care services (Department of Health 2004). This acknowledges the diverse and multiple experiences that children and young people go through. In response to the recognition of the diversity and multiplicity of these experiences, post-modernism with its association with diversity, difference and multiplicity has important implications for the ways in which the study was guided.

I wanted my study to be diverse in a number of ways, including the wide age range of children and young people, the range of both acute and chronic conditions experienced, and levels of support from parents and families. Thus it appeared that post-modernism with its sensitivity to difference, variability and multiple perspectives offered many potential benefits to carrying out research with children and young people by providing an opening to the exploration of the hidden dimensions of their experiences. However, the application of a post-modernist framework with its commitment to difference and congruency with current ways of thinking about children had clear implications for the ways in which the study was focused. For instance, it appeared that creating detailed aims for my study would both constrain and restrict children's and young people's opportunities to voice those aspects of hospitalisation which impacted most greatly upon their experience. Thus such an approach would result in certain perspectives remaining invisible through the imposition of my own adult-centred agenda upon the study. So in line with a post-modern approach I needed a framework which would be open to the very varied and possibly contradictory voices of children and young people. In response to this it appeared that a broad guiding question would be of most value through its potential to enable children and young people to express their own perspectives of being in hospital. Thus I created my guiding question which was to explore children's and young people's experiences of being in hospital.

In the next section I outline my rationale for selecting a qualitative approach.

The debate between constructivism and positivism

Previously writers have commented on the polarization of social science between positivism and constructivism, suggesting that the ensuing arguments defending extremes of both are counterproductive for either qualitative or quantitative research (Appleton and King 2002, Guba and Lincoln 1994, Corner 1991, Bryman 1988).

Positivism encompasses the philosophy of the natural sciences and historically has been accepted as the benchmark for all scientific research, including that of the social sciences (Mackenzie 1994). Central to positivism, Mackenzie (1994) argues, is the concept of scientific method which highly regards theory testing and the accumulation of a body of scientific knowledge. Theories, such as these, which are guided by procedures, are thus open to testing and replication by the scientific community. As a result, people who esteem the positivist tradition may deride those techniques which are non-standardised as they believe that without carefully explicated procedures, responses cannot be interpreted in a reliable way.

However, an awareness of the limitations of positivism within some areas of study has been highlighted. In the words of Long (1984: 89):

> "... the problems of positivist methodology become even more pronounced when the range of enquiry shifts to the non-biological causes of ill-health, such as perceptions of health, access and use of health services, or aspects of doctor-patient relationships ... Reference to "intangibles" becomes frequent in any attempts at explanations; perceptions, intentions, meanings and rules need to be involved. Further, universal laws no longer apply where individuals may have different interpretations and definitions of a situation".

This argument was clearly relevant to the study in which I intended to apply a framework which explicated the meanings a situation has for individuals. I believed that the application of a positivist approach to this work would both restrain and restrict children and young people in verbalising their perspectives and those issues which are important to them.

Such a viewpoint has been highlighted by other writers. Most notably, Alderson (1993: 58) discussed research methods under the headings "hard" and "soft" science and highlighted the ways in which general laws, such as those ascribed to within positivism, underestimate children's abilities, motives and choices. Thus, the unsuitability of the positivist approach led to the exploration of an alternative approach, that of constructivism.

In direct contrast to positivism, constructivists argue that "in a subjective world, where understanding and knowledge are symbolically constructed and held in convention and social unity with others, it is inappropriate to seek samples, control and isolate variables, quantify behaviour and generalise to a larger population of people" (Greig and Taylor 1999: 37). Instead, this approach attempts to enter children's worlds, then describe and analyse the contextualised social phenomena found there. Therefore, the constructivist believes that numbers do not adequately convey the actions, thoughts, themes and meanings of children and as Hatch (1995: 122) proposes:

> "Instead of control, constructivists want naturally occurring social behaviour, in place of isolated variables, they seek a contextualised holistic examination of participant's perspectives, instead of measuring, correlating and predicting, constructivists describe and interpret".

Thus, in applying the principles of constructivism to work with children and young people, this framework would determine the nature of the child as being subjective and not objectively measurable. Importantly within this approach, children and young people are acknowledged to have their own perspective. The constructivist approach is one aspect of an approach termed as qualitative.

The selection of a qualitative design

Darbyshire (1992) suggests that within both the fields of social sciences and nursing the case for qualitative research has been convincingly demonstrated. In an overview of the historical background to qualitative research in nursing he comments that "early attempts to shift nursing's worldview from a dominant logical-positivist position to a more humanistic and naturalistic one" by the early humanistic theorists, have been built upon by others. These include Benner (1984) and Parse (1981), "each of whom has developed an interpretive perspective on nursing but from different philosophical origins" (Darbyshire 1992: 34). This led Darbyshire (1992: 35) to comment that nurse researchers should no longer question if qualitative methods should be used, but instead "when, and how best should they be used"?

The qualitative research framework is based on assumptions about the subjective nature of children. Grieg and Taylor (1999: 43) elaborate that the qualitative approach:

> "… is based on the scientific activity of induction – the procedure for generating new theories and in which theory emerges from the data. The notion that theory is created from or emerges from data is consistent with the view that the child is subjective in nature and that his understanding, knowledge and meanings are subjective, and emerges in interaction with others in a given context".

Thus, from an interpretivist standpoint of research with children and young people, researchers seek to understand the social world from the point of view of the child within it. This approach attempts to make sense of how children and young people understand their experiences whilst acknowledging the need to "understand and capture subjective experiences and meanings" (Grieg and Taylor 1999: 43).

In choosing a qualitative design I was guided by the identified limitations of quantitative methods when considering the aims of my study. In line with the re-conceptualisation of childhood, it was clearly important to apply methods which were effective at illuminating children's and young people's experiences, perceptions and understandings of being in hospital. I believed that a quantitative approach which served a restrictive framework of quantification, would only isolate and reduce children's and young people's voices within the research process.

The complexity of children's experiences of being in hospital where parents, family members, nurses, medical and other hospital staff share in children's and young people's experiences, had a further important influence on the choice of a qualitative design. I believed that a detailed study of a small group of children and young people in order to understand the complexities of their experiences would be more valuable than attempting to use quantitative methods which would demand the categorisation of data into numeric terms.

The benefits of a qualitative design

Past studies have demonstrated the benefits qualitative techniques can offer in successfully promoting communication between children, young people and researchers. These include the in depth exploration of children's experiences and ideas whilst offering opportunities for complex issues to be highlighted by children themselves (Royal College of Nursing 1999). I was guided also by the re-conceptualisation of childhood and the application of an approach that would enable children's and young people's own perspectives to be heard. In addition, techniques based on the qualitative design allow the researcher to respond flexibly to those factors which may influence children's and young people's expressions of their views. Thus, the rationale for applying a qualitative approach to this study was as follows:

- The aim of this approach was to illuminate experiences deemed important by children and young people themselves and thus it is aligned to the qualitative approach.
- The study intended to explore the experiences of children and young people within the context in which the experience took place in order to highlight the ways in which the hospital setting both enhanced and impinged upon children's and young people's experiences. Thus the approach needed to embrace context which qualitative approaches do.
- A qualitative approach would allow for flexibility in data collection in order to meet the specific needs of individual children and young people. This would enable children and young people to determine the direction taken during an interview thus avoiding the limitations that pre-determined data collection structures would impose. Furthermore, flexibility within data collection offered the opportunity to use a wide range of methods of data collection suitable for children and young people of varying age ranges and abilities. This was important within this study where attempts were made not to preclude children or young people on the basis of their abilities which may have been affected due to the effects of long-term illness, or those children who had special needs or disabilities but were able to communicate verbally.
- The philosophy underpinning qualitative methodology acknowledges the role played by the researcher and the dynamics of their interaction with children and young people on data collection. This was of value to the study where, through a reflexive approach, the researcher's role and impact on the study would be acknowledged and demonstrated.
- The recognition that individual children's and young people's accounts of experiences may help to change established practice and develop new understanding was an important and desired outcome of the study and again is congruent with the qualitative approach.

- The acknowledgement of the value of working in partnership, in this instance with children and young people, providing them with opportunities to vocalise their experiences also had a greater resonance with adopting a qualitative approach.
- In an attempt to respect the rights of children, enabling children and young people to participate both to the extent they wished and through the ways in which they chose to be involved was also seen to be more effectively achieved through a qualitative approach.
- The belief that the voices of children and young people are central in understanding diversity and difference could be explored most appropriately through the adoption of qualitative methodology.

I next justify my selection of the ethnographic approach for the study.

The ethnographic approach

As discussed previously, the complexities inherent within children's and young people's experiences of being in hospital were an important influence on the chosen approach. Complexity can be seen in the ways in which the relationships between children, family, professionals, environment and resources contribute to, affect, effect and impinge on both care and children's experiences of being in hospital. Therefore, it was clearly important to carry out the study in the context in which it occurred if these interrelated elements which impact upon children's and young people's experiences were to be identified. I believed that it was important to consider the accounts of children and young people within the context of the wider social structure in which children's health services are provided and the ways in which organisational approaches to care may impact upon the experiences of children. This appeared to relate well to exploring the opportunities open to children and young people to act as consumers of care.

The notion of studying the perspectives of children and young people within the context in which they occurred was an important influence in my final choice of ethnography as the approach to the research. Ethnography can be viewed as both a method of data collection and as a philosophical framework designed to explore how people interpret their experiences of the world (Hammersley and Atkinson 1995). For many ethnographers it is centrally important that the findings convey a sense of "being there"

(Savage 2006) and include recasting everyday understandings and practices that are taken for granted, or turning the familiar into the strange (Dixon-Woods, Young and Heney 1999). Ethnography has been defined as:

> "... concerned with gaining the perspectives of numerous and differently positioned individuals, giving attention to power, inequality and how some voices are heard above others" (Savage 2006: 385).

The choice of an approach that deliberately aims to hear how some voices are more powerful was important and resonated with the values of exploring diversity and power as previously presented. Furthermore, ethnography has been shown to enable children to contribute to research in their own time and ways (Emond 2006, Laerke 1998, Fine and Sandstrom 1988, Bluebond-Langer 1978).

The assumptions of ethnography

Mackenzie (1994) draws on the work of Schatzman and Strauss (1973) and Lofland and Lofland (1971) to outline how the assumptions which underpin the ethnographic approach describe a particular epistemological stance drawn from naturalism. These build upon the work of Silverman (2005) and Hammersley and Atkinson (2002). A summary of these assumptions is provided by Hilton (1987) who proposes that; a person's behaviour is inextricably linked with the meaning that the situation has for her; a person's understanding, and hence behaviour, changes as she interacts with others; within a situation there will normally be different perspectives; a person's behaviour and beliefs can only be fully understood in the light of broader aspects of organisation or culture; and the group or culture must be studied "as it is".

Through its commitment to exploring the meanings that experiences have for individuals and the emphasis placed on the multiple perspectives which may exist within any given situation, ethnography can be seen to have several links with symbolic interactionism. Importantly also, ethnography appeared to be well equipped to manage the demands a complex study was likely to encounter.

Several of the assumptions underpinning the ethnographic approach were influential in the choice of this approach. Firstly, ethnography has been defined as a means of gaining access to the health beliefs and practices of a culture, thus allowing the researcher to view the phenomena in the context in which it occurs (Morse and Field 1996). Indeed, it has been argued that the ethnographic focus on culture, which can be more completely captured using this design, sets it apart from other methods (Laugharne 1995). Many ethnographers believe that human behaviour can only be understood within the context in which it occurs (Robertson and Boyle 1984) as it is assumed that a person's behaviour is inextricably linked with the meaning that a situation has for him or her (Hilton 1987). The context in which children and young people experience health care is clearly important when considering their accounts. Health and illness behaviours occur within a total cultural context, no part of which is entirely independent on other parts. In addition, social, political and economic factors influence health care delivery, strategies and resources to a great extent. If viewed from an ecological perspective these would be regarded as macro effects. Clearly the organisation and funding of children's services are among the structural factors which may impact upon children's and young people's experiences. I believed that the ethnographic approach would enable those factors which impinged upon children's and young people's experiences to be taken into consideration. Such a contextual exploration of children's and young people's experiences within the hospital setting would enable insights to be gained which were sensitive to children and young people themselves.

Secondly, ethnography allows children and young people to be viewed as both competent informants and interpreters of their own lives whilst placing children's and young people's own accounts centrally within the analysis (James 2001). I believed that this approach, which would enable children and young people to voice their experiences of being in hospital and allow these accounts to be explored, was particularly relevant to this piece of work.

Lastly, I acknowledged that the application of the ethnographic approach would enable differing perspectives between myself as a researcher and an adult to be clarified through an understanding of being in hospital from the perspectives of children and young people themselves. This was clearly important in ensuring that the perspectives of children and young people were accurately reflected. In terms of consumerism, the insider view has distinct implications for service provision as children and young people are cared for within a framework imposed by adults. Thus, seeking children's and young people's views in this way recognised their abilities in influencing their own care and shaping the future care of others.

Summary

In this chapter I have outlined my case for choosing symbolic interactionism as the theoretical framework and my rationale for selecting the ethnographic approach within the qualitative paradigm has been explicated. In the next chapter I move on to describe the methods of data collection and the research design.

CHAPTER 4:
METHODS AND DESIGN

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> "As adults representing children we can try to recognise the ways in which our researcher status may confound and exploit our adult status and clarify whether we are representing children in the realist, photographic sense of portrayal or using our political perspective to make judgements about the way they are represented as we engage in struggles about "recognition" or meaning" (Alldred 2000: 167).

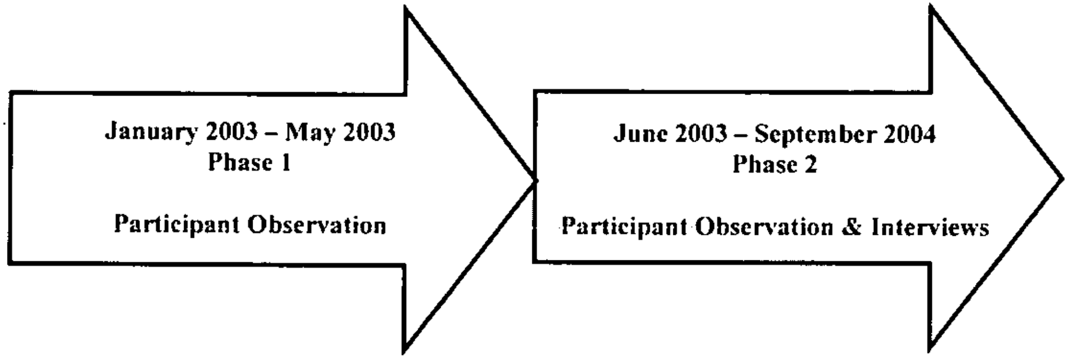
Introduction

In this chapter I summarise the ethical principles that guided this study, focusing in particular upon issues around power and consent and assent. I place this section at the beginning of this chapter as it is integral to situating children's and young people's voices central to the study. I next describe the selection of the research participants before outlining the data collection methods in which they participated and discuss the issues around using these particular methods in research with children and young people. Next I outline the process of data analysis, exploring the issues around the interpretation of qualitative data, particularly with children. Lastly, the ways in which the principles of worthwhileness and credibility were applied to the study through a reflexive approach are outlined.

I integrate the literature around methods and design within this chapter, presenting what my initial plans were and how these worked out. Aligned within an ethnographic approach I present this as a journey, drawing upon field notes and my experiences of data collection alongside the literature. I include field notes alongside data when illustrating some points.

Outline of the structure of the study

A diagrammatical outline of the study is presented in figure 4.1 describing the first phase of preliminary participant observation, second phase of participant observation and interviews, hours of participant observation within both phases and numbers of interviews, illustrations, activity sheets and pages of field notes incurred.



Phase 1: 100 hours of participant observation
Phase 2: 175 hours of participant observation
46 interviews with children and young people
27 illustrations
63 completed activity sheets
730 pages of field notes

Figure 4.1 Outline of structure of study

Ethical considerations

With regard to discussing the ethical considerations of a study, writers have commented that "merely reporting Ethics Committee decisions is an insufficient response to the particular ethical issues inherent within the qualitative or interpretative research paradigm" (Darbyshire 1992: 61). Carrying out research with children has special ethical implications which deserve detailed discussion. I will address this section by describing the process of gaining ethical approval for the study before discussing in more detail those ethical implications which merit special attention.

Prior to beginning the fieldwork in January 2003, a proposal was submitted to the relevant Research Ethics Committee of the Trust in which the study was conducted[2]. Formal approval to proceed was granted prior to data collection. Permission to undertake the study was sought also from senior nurse managers and the Research Development Manager at the hospital. Each consultant involved with the study setting and the ward sister also were contacted and informed of the study in order to gain their approval. Approval was subsequently obtained from all parties.

As Darbyshire (1992) comments, these are the formal, procedural steps taken to ensure a sound ethical basis for the study. However, "this kind of "bare bones" information tells only half a story" (Darbyshire 1992: 56). In examining the ethical implications of

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[2] Prior to this the proposal went through the University Faculty of Health Ethics Committee.

carrying out research with children the issues of power, informed consent and confidentiality are salient issues. I will next move on to discuss these in some detail.

Issues of power

Robinson and Kellett (2004: 84) acknowledge that "power relations in child research are reinforced by more general cultural notions that exist between children and adults in society at large". Furthermore, the ward environment in which the study was carried out could be viewed as a setting where children were potentially "captive subjects"; that is, in an environment where the balance of power is heavily skewed towards adults and where children and young people may be least able to exercise their participation rights.

Particularly within the context of research governance and ethical review, children are deemed to be vulnerable (Carter 2009). Indeed, Kortesluoma, Hentinen and Nikkonen (2003) comment that children in hospital are even more vulnerable due to their illness, being in pain and being in the hospital context itself. However, as Carter (2009) comments, acknowledging children's vulnerability should not preclude them from participating in research. It was imperative, however, that children and young people involved in the study were treated with respect, with special consideration being paid to the power relationship between adult researcher and child and/or young person.

Other writers have previously explored the issue of power in relation to carrying out research with children. Corsaro (1981: 118) for instance, in considering his power as researcher, noted that, "... adults are much bigger than children and are perceived as being socially more powerful". Aside from the physical differences between adults and children, Corsaro comments that age and authority separate adults and children, this qualifying his participation as only partial. However, the power divide between children and adults is wide and would suggest that the measures that we as adult researchers can take to reduce the power imbalance, whilst important, are limited. Alldred (2000: 159) highlights the power imbalance between researcher and child interviewees and is "modest about the extent to which it can be rectified. ... if one is not a child, can one and should one attempt to understand and convey what children's experiences are?"

In her discussion of a research study carried out with children, Mayall (1996) elaborates this further. This author describes the child friendly measures she took during the interaction and reflects upon her position as author of "children's accounts", acknowledging that the argument she puts forward is her own. Alldred (2000: 152), meanwhile, writes of the existence of an unequal power relationship in the later stages of the research process. She comments:

> "Not only are adult researchers "... perceived as being socially more powerful", they are more powerful by virtue of their role as researchers, through which they are in a position to interpret, as well as to represent".

Measures, such as those advocated by Kirk (2007), taken in relation to empowering children and young people within data collection, included talking with them prior to the start of the interview about the ways in which they could initiate breaks, ask for explanations, decline to answer certain questions and stop the interview. These measures were child centred and included, for example, cards the children and young people could hold to request to temporarily stop or terminate the interview. Where children/young people gave agreement to be recorded, they were given control of the tape recorder and invited to begin or stop recording as they wished in order to empower them in the research process as advocated by Mahon et al (1996).

Christensen (2004) calls for a consideration of whether the concept of being a research subject makes sense to children and how it may be made to reflect their experiences and perceptions and be understood within the context of their everyday lives. It has been noted that children's responses may highlight experiences important to their own lives rather than explicitly revealing direct answers to research questions (Barker and Weller 2003). Within my study I intended that children and young people themselves would play a large part in determining the agenda of the interview, thus enabling them to talk about the issues related to being in hospital which they themselves considered to be of importance. Thus I proposed that the interviews would be determined by the children and young people themselves in that they would choose how the interview was conducted, whether through verbal account only or through talk alongside play and/or activity worksheets. The medium of play and the worksheets themselves were intended to again be chosen by each individual in order to empower them throughout the interview process. Thus before beginning the interview, I showed children and young people the range of worksheets and play activities in order to provide them with a range of choices. Children and young people themselves chose which activities to undertake, some deciding at the beginning of the interview and others as the interview progressed.

For those making choices before the interview commenced, their decisions sometimes shifted as the interview evolved. Whilst the activities and worksheets were designed carefully to help contribute to the generation of data, the more important role that these activities and worksheets had was to empower the children and provide them with opportunities to exercise choice, control and decision making and allow them to take an individual route though data collection process. However, the activities greatly added to the breadth and depth of the data generated.

In a further attempt to address the power imbalance, I planned to give children the opportunity to choose whether a friend or family member was present during the interview. Irwin and Johnson (2005) describe parents' contribution of giving prompts to children during interviews as adding "scaffolding" which can add to the child's narrative.

Within the presentation of the thesis I attempt to mediate the power imbalance by integrating illustrations and activities from children and young people into the text and not giving primacy to the spoken or written word. In doing this I acknowledge the value of alternative avenues of expression by children and young people.

Issues of assent and consent

One of the most important considerations in this study was that participation was based on the principles of informed assent for children and informed consent for parents. Due to the legal implications surrounding consent issues with children (Valentine 1999), important distinctions have been made between a researcher gaining "consent"; that is, where someone voluntarily agrees to participate in a project, based on full disclosure of pertinent information, and "assent"; whereby the parent consents to allow their minor/child to participate in a project and the child assents or agrees to be involved (Tymchuk 1992). I will continue by describing assent in more detail as it was a central element of the study.

Assent

Assent differs from consent in fundamental ways. It is defined as an affirmation to participate in research (Broome and Stieglitz 1992) and is a co-operative process between children and researchers involving disclosure and discussion of a research project. Unlike consent, assent is not a legally mandated process (Lindeke, Hauck and

Tanner 2000). Instead, even if children do not have the maturity or experience to give fully informed consent to participate in research, they can express a desire to be either included or excluded. It requires that children have a basic understanding of the research process and are informed about what they are expected to do. It implies that children understand what will be done to them and have been given the opportunity to express their preference regarding participation (Mitchell 1984). The process is guided by an assessment of children's developmental maturity and is not based on age or legal competency (Lindeke, Hauck and Tanner 2000).

Consent and age

One of the obstacles in the path of participatory research with children is the use of age as a delineating factor in competence (Robinson and Kellett 2004). Valentine (1999) comments that the notion that children cannot or should not consent is derived in part from Piaget's (1952) concept of children as passing through a series of age related stages of development. It therefore "assumes a qualitative difference between the competence of children and adults to consent, rather than placing the emphasis on what knowledge they have and how they use this knowledge" (Valentine 1999: 143). Clearly, age can still be viewed as a widely used factor in determining ability to give consent. For instance, the Children Act (1989) comments that Courts have to have regard in particular to the ascertainable wishes and feelings of the child concerned, considered in the light of his age and understanding. However, using a child's chronological age to determine ability to give consent raises important issues and is now widely contested.

The Gillick ruling

In examining age in relation to consent the Gillick ruling is particularly important. This complex case developed a legal definition of the child's competence to consent known as "Gillick competency". Wheeler (2006) draws attention to the fact that Research Ethics Committees often insist upon the use of "Fraser" rather than "Gillick competency" believing that this term is unwelcome to Victoria Gillick. However, Wheeler states that this is not the case and that "Gillick" and "Fraser" are not interchangeable as Lord Fraser's guidance is narrower and relates only to contraception whilst "Gillick" provides the detailed assessment of the child's capacity. "Gillick competency" states that a competent child is one who "achieves sufficient understanding and intelligence to enable him or her to understand fully what is proposed" and that the competent child has "sufficient discretion to enable him or her to make a wise choice in his or her own interests" (Morrow and Richards 1996: 95). This definition is important because it moves away from the notion that it is biological age that determines competence. Rather, Valentine (1999: 143) writes:

> "competence to consent is predicated upon three factors: a child's understanding of relevant information, wisdom (ie, the ability to make a choice in own best interests) and freedom or autonomy to make that voluntary choice without coercion. It is therefore contextual and relational rather than developmental".

However, when examining the Gillick ruling important issues are raised including how competence is assessed, particularly by researchers, and when does a child have the ability to fulfil the Gillick competency criteria? Competence at a practical level is difficult to define, assess or measure and is dependent on many factors. In practice, Brook (2000) argues that the complexity of assessment can lead clinicians to take the easier option of assuming that adults are competent and children are not.

The retreat from Gillick

Despite the Gillick commitments concerning rights to consent, Alderson and Montgomery (1996) acknowledge that these have been seen to be drastically devalued by judicial interpretation. Rulings in the Court of Appeal (see Alderson and Montgomery 1996: 34-35) appear to revoke the child's right to consent, allowing one or both parents to overrule their consent and indicating that the Gillick competent child may be listened to but their wishes overruled. As Alderson and Montgomery (1996: 34-35) write:

> "the right to consent has been shown to be a fragile right that can easily be destroyed. Its very existence depends on being "Gillick competent" but that capacity is judged by adults... Rhetorical respect for autonomy rights go hand in hand with willingness to remove them from individual young people on the basis that they are not competent to exercise them. In effect, the promise of Gillick is made but not honoured".

Application of Gillick competency to gaining consent from children and young people for research purposes

Lansdown (1998) comments that the law in relation to consent and children is simple in that it comes up with the notion of a competent child and complex in that the definition of competent is far from clear. For instance, the Children Act (1989) theoretically allows a child of sufficient understanding to refuse to submit to a medical examination. In practice however, this is often not the case. Thus how can Gillick competency be applied to the issue of gaining consent from children for the purposes of research? Valentine (1999: 144) writes that the Gillick ruling appears to:

> "make it legally acceptable in the UK for a child to consent to participation in social research; although in this interpretation of the law parents can still also give proxy consent, but this appears to be only legally valid if it is considered to be in the best interests of the child... However, UK law in relation to consent to treatment and research remains very uncertain. Subsequent cases and appeals, rather than clarifying the legal situation by reinforcing the 1985 Gillick law lords, have if anything muddied the waters by turning against this judgement".

In response to this, given that the UK law has been defined through cases involving children's consent to medical research and treatment rather than social research, authors advise caution suggesting that social researchers ask for consent from both parents and children, rather than either one or the other (Piercy and Hargate 2004, Alderson 1995). This study also draws upon more recent guidance around consent for undertaking research with children (see Twycross, Gibson and Coad 2008, Gibson and Twycross 2007, Medical Research Council 2004 and Royal College of Paediatrics and Child Health 2000). In view of this, the study used the principles of both assent and consent. The measures undertaken to ensure informed assent and consent were as follows.

The study was sensitive to the individual needs of children and young people at all times and thus no attempt was made to approach children or young people when they were either in pain or distress. Upon arriving on the ward I spoke with the nursing staff in order to determine ages of children on the ward and any children I should not approach, for example, those who were particularly unwell. Following this I firstly approached parents of children and young people eligible to be included in the study in order to gain verbal permission to speak to their child regarding their potential involvement in the study. Where this was given, I spoke with the child and parents together informally and the purpose of the study was explained both verbally and in written form[3]. Time was given to allow children and parents to consider their decision.

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[3] Specially designed information leaflets were developed, encompassing a range of different capacities and development stages. Throughout the study, I assessed children individually in order to determine which leaflet was most appropriate for their abilities. See appendices 2-6 for examples of children's, young people's and parents' information leaflets.

Where parents gave their consent for their child to be included in the study children were asked individually for their assent to be involved. At this time, both children and parents were asked to read separate assent[4] and consent forms[5]. With some younger children and those with learning disabilities I read the assent form out loud with them. At this time, I also clarified children's understanding of both the verbal and written information to ensure that they fully understood the purpose of the research and were able to give informed assent. I was careful throughout the assent/consent process to emphasise to both children and parents that they were under no obligation to take part in the research, that they may withdraw at any time and that such a decision would in no way compromise on-going care. It is important however to include here the complexities of carrying out research in a busy clinical area. Excerpts from the field notes describe these:

> [The impact of parents not being available has made me think about attending the ward at a different time which is a step I feel I need to take. It also made me think about the ward as being constantly evolving and changing as previously the morning had resulted in many children being available for interviewing. Today has also highlighted the complex nature of gathering data in the ward setting. The name board doesn't provide any indication of ages and so I need to walk around the bays to gain an insight into ages and parental presence. It is also difficult to identify ages of patients in cubicles as curtains cover the doors and I need to physically enter to determine this. Specific issues that stand out in my mind today are approaching a mother of a child I thought was in the study age range (as a boy of approximately five-six years was sitting on the bed playing computer games). The mother was holding a baby on her lap and it was only as I approached her that I realised that it was this younger child who was actually hospitalised. In fact, this family would have been unsuitable anyway as they were non-English speaking. A second key issue was waiting outside the cubicle of an older child who would have participated although his parents weren't actually present. The child in the cubicle opposite was causing the doctors some concern. I just felt so relieved that I hadn't approached this child although upon asking the staff they reassured me that there was no-one that I couldn't approach. Lastly, my approach to a boy who refused to participate very politely felt traumatic for me, not because of his choice, but because I tried to speak to him and his mum at the same time whilst trying to elicit the mother's approval first to approach her child. She responded very nicely with, "don't ask me, ask ....". I feel frustrated with the position I have to take due to the Ethics Board's stipulations. I feel that I'm

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[4] Similarly, assent forms for children were developed encompassing a range of capacities. See appendices 7-9.

[5] See appendices 10-12. Parents gave their consent for participation in both the preliminary phase observation and later, the full study. The hospital Trust requested also that parents completed the Trust consent form.

> trying to carry out research with children and young people in order to empower them and yet the execution of the study itself disempowers them as the choice to participate is firmly placed in the adult's (parent's) domain] (Fieldnote). [6]

Issues of power in relation to assent

An exploration of the issue of power and how this impacts upon the opportunities open to children to assent to research warrants further discussion. Like Moore, Beazley and Maelzer (1998), I recognise the imbalance of power which exists between children and adults and which often functions to determine a child's access to, or alienation from, the research process. As Moore, Beazley and Maelzer (1998: 78) comment:

> "... even when attempts are made to invite children to participate in projects in their own right, the issue of consent is opaque. (Where initial approach is to parents) ... any expression of interest in the project and subsequently any decision to participate, or desist, (is) not explicitly the child's. Rather, children's consent (is) a product of the attitudes of their parents... Clearly, a child's right to be heard is easily diluted".

Thus questions arise regarding the assent process when, as in this study, parents must be approached and their consent obtained prior to discussing a research project with the participants themselves, children and young people. For instance, a child might agree to please or appease a parent. Conversely, refusal to participate may occur in order to exert independence from a parent and not through lack of interest in the project (Moore, Beazley and Maelzer 1998). However, I could find no way to solve this dilemma other than ensuring that children assented to the study and appeared willing to be involved throughout periods of data collection through the measures discussed previously.

Confidentiality

Confidentiality has been a key principle of the study. All data has been treated as confidential and anonymous. Confidentiality regarding the personal details of children has been respected and all data have been anonymised so that nothing will be traceable back to individual children and young people. Alongside individual confidentiality, I attempted to ensure that the location of the research site was known only to the respondents and those involved in the study.

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[6] This extended field note is included as it reflects upon particularly frustrating and difficult events.

Issues surrounding anonymity and confidentiality have important implications in research with children and young people. Consequently, where a child divulges that they or others are at risk of significant harm a duty exists to safeguard the child or others. Whilst it appeared unlikely that information of this nature would be revealed throughout the course of the study, it was explained to children, young people and their parents that the emergence of such information would have to be shared with relevant other professionals. Therefore, channels for the referral of such children to counselling and support services were identified prior to commencing data collection. Whilst no information of this nature was revealed, two young people revealed details of being bullied and one of being pressured to have under age sex. However, this was information either parents or the ward staff were already aware of. In his discussion of the issues surrounding confidentiality, Darbyshire (1992: 59-60) draws an interesting parallel between the benefits and limitations of anonymity. He writes:

> "It may seem paradoxical, but for interpretive research which seeks to uncover and describe lived experience, this anonymity must also be considered to be a limitation of the study. The participants have necessarily lost much of the rich personal detail which helped to make up their particular context and personhood. When their individuality is stripped away to reduce them to merely "Mrs A", "Mr T" or "Nurse S" it is as if the person has been lost to confidentiality. I saw no way to resolve this dilemma which would have ensured both confidentiality and a fuller personal biography and therefore accepted this as a necessary, if unfortunate trade-off which must be made in research".

Clearly this dilemma is equally applicable to the position of children within research. However, like Darbyshire, I accept that there is no way in which this dilemma can be solved whilst maintaining confidentiality. Therefore, I have addressed this issue by ensuring that children and young people were aware of my commitment to maintain their anonymity and the ways in which this impacted on report writing at the time of gaining their assent to the study.

Selection of the research participants

The selection of children and young people who participated in the study was flexible with the aim of identifying and involving those children who wished to take part. In selecting children to be involved the ethnographic literature and in particular the work of Mackenzie (1994: 777) proved valuable:

> "The purpose of sampling in ethnography is … concerned not only with the selection of key informants to give insight into the phenomena under study, but also with sampling across time and place. … This purposive sampling is a form of comparative method whereby emerging ideas ... may be tested out in different contexts or within different groups, thus refining constructs and discovering or developing categories".

Applying the purposive method of sampling to the study appeared to offer many benefits. This included the selection of children and young people who had knowledge and experience of the hospital setting alongside those who had very little. I believed that this would offer opportunities to gain important insights into the perspectives of children and young people. Another key element of purposive sampling is the opportunity it provides to pick up different areas of children's and young people's experiences which were of relevance, as well as other categories that may emerge as significant in on-going analysis. Such an approach allowed for emerging themes to be checked out with other children in different contexts, and is strongly advocated within the ethnographic approach.

Whilst being aware of the importance placed within ethnographic texts on the concept of the "key informant" by influential writers including Leininger (1985) and Field and Morse (1985) and recognising the value such participants can offer to the study, I hesitated to select "key informants" within the study. Despite the advantages these key children and young people could provide I was influenced by Darbyshire in his rejection of these key informants:

> "I rejected the strategy of selecting only "key informants" for several reasons. The very term suggests that there are other informants who may be "non-key informants" and such a presupposition seemed contrary to the exploratory and discovery spirit of the study. More practically, I had no way of knowing, even after familiarising conversations, who would prove to be the "best" informant during interviews. A further danger inherent in the key informant strategy was that "key" may be assumed to be synonymous with articulate, extrovert or with those who seem to have the most dramatic accounts to offer" (Darbyshire 1992: 45)

Whilst I identified with the reasons put forward by Darbyshire, it was the latter point that concerned me the most as I embarked on the research. I was aware that carrying out research with children and young people called for special consideration in all parts of the research process. On a personal level, I strongly believe that children and young people should be given the opportunity to voice their experiences and to have these accounts listened to. Therefore, this was an important theme which I intended to follow throughout the study. I was aware, however, of the ways in which children's and young people's voices are often not heeded. I recognised also that certain groups of children, such as those suffering from chronic illness, or those with special needs, are marginalised even more so in research terms. Alldred (2000: 165) describes the ways in which children's accounts may be disregarded if research involves child participants who are speaking of complex, or emotional experiences:

> "The complexity of issues that we face is illustrated by the fact that these same psychological discourses of the subject which allow some children to be heard will disallow other children, including those who present contradictory or illogical accounts and don't manage to make themselves understood by (particular) adults, in "adults" terms".

This appeared to especially relate to the nature of this study whereby children's and young people's experiences of being in hospital may be both emotion-laden and of a complex nature. As a result this raised particular concerns that the use of "key informants" in conducting research with children and young people, particularly in an area where many are already disadvantaged in research terms due to on-going illness and disabilities, may perpetuate the process of the marginalisation of these groups of children and young people. For this reason, I chose to reject the strategy of selecting only "key informants".

In order to optimise the opportunities available to understand and explore children's and young people's experiences of being in hospital[7], children and young people with a range of both acute and chronic illnesses and disabilities were invited to be included. I anticipated that children's and young people's previous experiences of hospital and their familiarity with the hospital environment would impact on the ways in which they experienced being in hospital. For this reason, children and young people with a wide variety of hospital experiences were invited to be involved alongside those with little experience (see table 4.1). As can be seen the children and young people who participated in the study were diverse in terms of age, gender, ethnicity and cognitive ability. However, I have deliberately chosen not to keep highlighting the condition or health needs the children and young people were presenting with, unless making a

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[7] The study was set in a children's hospital.

specific point, as my focus is upon children's experiences and perceptions and not specifically upon their conditions.

The diversity of the children and young people cared for within the ward was an important influence on my choice to use it as the setting for the study. Firstly, the accommodation of children and young people with a wide variety of illnesses and conditions avoided a concentration on a very narrow group of children and young people, which may have been the case if the study was conducted in a ward concerned with a specific medical speciality or a district general hospital, where possibly children and young people with highly complex needs would be the exception rather than the norm. Secondly, the specialist facilities offered by the hospital had an important influence in terms of exploring children's and young people's experiences. In this I recognised that this particular ward setting would provide a varied pattern of resident parents/families in relation to pressures of travel and finance, alongside more common familial factors. Lastly, further diversity within the children and young people in terms of length of stay would be an important factor in exploring children's and young people's experiences. I believed that such diversity within the study would lead to a greater understanding of the complex nature of being in hospital through the breadth and depth of experiences these children and young people would be able to share.

Children and young people from a number of ethnic minority groups participated within the study.[8] Some of the children and young people who participated in the study had learning disabilities. This information has been included in table 4.1. However, by including this information I am not aiming to be divisive or to suggest difference, but instead wish to show that the study was inclusive. In order to identify individuals when they are quoted in the main text, each child and young person has been assigned a number in the demographic chart which is stated alongside their name in brackets within the main text.

Further diversity was added in that children and young people over a wide range of ages were invited to take part in the study. In making this choice I anticipated that age would be an important factor in children's and young people's experiences of being in hospital. Children and young people between the ages of five and sixteen years were

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[8] I do not categorise children and young people by ethnicity but acknowledge that my sample came from across different ethnic groups and focuses upon their experiences. My sample was not large enough to consider whether particular experiences were intrinsic to different ethnic groups.

Table 4.1[9] Demographic data

Name	Gender	Age	Acute / Chronic	Condition / Reason for admission	Past Hospital experience	Day of admission at interview	Resident Family
1. Abby	Female	9y	Chronic	Cystic Fibrosis Surgery	Frequent admissions	Day 2	Mum
2. Anna	Female	7y	Acute	Learning disabilities Chest infection	Second admission	Day 5	Mum
3. Anya	Female	15y	Chronic	Cystic Fibrosis	Frequent admissions	Day 4	None
4. Alfie	Male	8y	Acute	Cerebral Palsy Learning disabilities Urinary tract infection	First admission	Day 2	Mum
5. Benito	Male	6y	Acute	Urinary tract infection	First admission	Day 2	Mum
6. Callum	Male	15y	Chronic	Cystic Fibrosis	Frequent admissions	Day 7	None
7. Charlie	Male	11y	Acute	Pre-existing cardiac condition Vomiting & dehydration	Frequent admissions	Day 5	None
8. Charlotte	Female	16y	Chronic	Cystic Fibrosis Intravenous antibiotics	Frequent admissions	Day 5	None
9. Daisy	Female	6y	Chronic	Eczema	Second admission	Day 3	Mum
10. Dominic	Male	13y	Acute	Road traffic accident	First admission	Day 10	Mum
11. Elena	Female	14y	Chronic	Cystic Fibrosis Colonoscopy	Frequent admissions	Day 2	Mum
12. Elijah	Male	8y	Acute	Diabetes Diarrhoea & vomiting	Second admission	Day 2	Dad
13. Emily	Female	12y	Chronic	Crohns disease	Frequent admissions	Day 4	Mum & sister
14. Florence	Female	10y	Acute	Vomiting	First admission	Day 5	None
15. Georgina	Female	5y	Acute	Headaches	First admission	Day 2	Mum
16. Grace	Female	6y	Acute	Kidney infection	Second admission	Day 4	Mum
17. Hannah	Female	15y	Chronic	Cystic Fibrosis	Past admissions	Day 7	Mum
18. Harry	Male	10y	Acute	Learning difficulties Fitting	Frequent admissions	Day 4	Mum
19. Isaac	Male	13y	Chronic	Crohns Steroids	Second admission	Day 2	Mum
20. Isabelle	Female	14y	Chronic	Cystic Fibrosis	Infrequent admissions	Day 7	Mum
21. James	Male	12y	Acute	Urinary tract infection	First admission	Day 4	Mum
22. Joseph	Male	10y	Acute	Asthma	Second admission	Day 2	Mum
23. Joshua	Male	12y	Acute	Chest infection	First admission	Day 2	Mum
24. Katie	Female	7y	Acute	Urinary tract infection Intravenous antibiotics	Second admission	Day 6	Mum
25. Leila	Female	15y	Chronic	Ulcerative colitis	Second admission	Day 5	Variable
26. Libby	Female	12y	Acute	Chest infection	Third admission	Day 3	Mum
27. Louise	Female	16y	Acute	Remission-leukaemia Chest infection	Frequent admissions	Day 3	Mum
28. Luke	Male	10y	Acute	Orthopaedic surgery	Third admission	Day 1	Mum
29. Lydia	Female	10y	Chronic	Cystic Fibrosis Intravenous antibiotics	Frequent admissions	Day 9	None
30. Maija	Female	9y	Chronic	Crohns	Frequent admissions	Day 1	Mum
31. Malachi	Male	13y	Acute	Chest infection	Second admission	Day 5	None
32. Mia	Female	7y	Acute	Chest infection	First admission	Day 1	Mum
33. Milly	Female	9y	Acute	Asthma	First admission	Day 2	Mum
34. Minna	Female	5y	Acute	Chest infection	First admission	Day 1	Mum
35. Oliver	Male	13y	Acute	Asthma	Frequent admissions	Day 5	None
36. Olivia	Female	7y	Acute	Asthma	First admission	Day 2	Mum
37. Oscar	Male	11y	Chronic	Crohns	Fifth admission	Day 5	None
38. Paolo	Male	14y	Chronic	Genetic condition Epilepsy	Second admission	Day 2	None
39. Poppy	Female	6y	Acute	Fitting	First admission	Day 2	Mum
40. Saira	Female	9y	Acute	Cerebral Palsy Learning disabilities Chest infection	Frequent admissions	Day 4	Mum
41. Samuel	Male	16y	Chronic	Cystic Fibrosis Intravenous antibiotics	Frequent admissions	Day 2	None
42. Sarah	Female	11y	Chronic	Ulcerated leg	Fourth admission (one lasting for 6 months)	Day 12	None
43. Stephen	Male	12y	Acute	Eczema	Past admissions	Day 4	Mum
44. Violet	Female	9y	Chronic	Recurrent migraines	Fifth admission	Day 2	None
45. Yasmeen	Female	8y	Acute	Epilepsy	Third admission	Day 4	Mum
46. Yusuf	Male	11y	Acute	Surgery	First admission	Day 3	None

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[9] All the children's/young people's names are pseudonyms.

invited to take part. The extensive research work of Fivush in particular, in reporting that the autobiographical recall of children aged as young as five years has been shown to be both accurate and stable over time (Steward and Steward 1996, Fivush 1993, Fivush et al 1991, Fivush and Hamond 1990) was an important influence in making a decision regarding the involvement of younger children in the study. However, making a decision as to the upper age limit of young people to be involved in the study demanded careful consideration. Initially I believed that including children up to early adolescence (12 years) would be adequate in capturing those children who would most value sharing their experiences of being in hospital. However, young people too had important accounts to tell. Therefore, steps were taken to increase the age limit of children who could be invited to take part in the study from the relevant Ethics Committee up to sixteen years.

One difficulty prior to undertaking qualitative research is the anticipation of the numbers of participants who will be required in order to meet the aims or guiding questions of the study. In this, the literature surrounding qualitative analysis is explicit in commenting that data collection must continue until this, alongside data analysis, no longer reveals the emergence of new themes. This is referred to as "saturation".

Forty six children and young people participated in the study. However, the uncertainty in terms of anticipating actual numbers of participants prior to conducting qualitative research is problematic in instances where ethical approval is necessary for research. For this reason, researchers often have to make assumptions in relation to this, being cognisant of the fact that an anticipated sample size is particularly difficult to predict in advance of a study. Therefore, a range of between thirty to sixty children was quoted when applying for ethical approval for the study. In deciding upon this number I was guided by similar qualitative studies of this nature within the hospital setting successfully undertaken using sample sizes of between 57-62 parents and nurses (Callery 1995, Darbyshire 1992[10]). The nature of the topic under study is of relevance when determining sample size. I anticipated that the complex and diverse nature of being in hospital makes the topic multi-faceted, thus potentially requiring the involvement of a relatively large number of children and young people. Whilst it is clear that children and young people are able to provide accurate and valid data when appropriate methods are used, I anticipated that the amount of data gained from each

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[10] I realise that this study is now dated but draw upon it as it has resonance with my study.

child and young person might be limited by the need for relatively short times of data collection, the incorporation of breaks into conversations with children and young people and the use of a variety of methods, such as play and drawing.

Within this study, whilst the taped interview itself did not exceed half an hour, gaining rapport first with the children and securing assent and consent could take up to an hour in itself. Numerous examples such as these abound in my field notes and reflect in some way the nature of carrying out research with children:

> [Interviewee: Young person, male, aged 10 years. Mum resident throughout hospital admission. Has a mild degree of learning difficulties although he is very articulate and able to verbalise his experiences. Due to this I chose to use the information sheet and assent form for the slightly younger age group which, I feel, was the right choice. We read through these together and spent more time on them than perhaps in other interviews, in particular for me to clarify the young person's understanding. Mum and dad demonstrated trust in me by giving their consent first and then leaving me with their son to attempt to gain his assent whilst they left the ward for breakfast. This resulted in me feeling much more anxious to ensure that he understood fully about the study and his part in it. However, the young person was very keen to be involved and seemed to relish the attention he was getting and thoroughly enjoyed reading the study leaflets together. We spent a lot of time doing this. Prior to leaving the ward, mum commented that he hadn't spoken much yesterday due to having fits and emphasised how talkative he was with me. We talked for a while about Harry Potter and Cinderella before talking properly about the research. This increased my confidence and made me feel that I had been able to build up rapport with him. The young person was very talkative all throughout the interview. I also felt pleased that the young person had felt able to be left alone with me whilst his parents were away and touched by the trust they demonstrated in leaving me with him] (Fieldnote).

Description of data collection methods

Introduction

Darbyshire (1992) comments that it is important that the data collection methods used within the study arise from the discussed theoretical position. In order to enhance the "trustworthiness" of qualitative studies it has been recommended that the researcher make explicit the "decision or audit trail" in order that others may have a clear idea of the rationale behind the methodological and interpretive decisions taken (Guba 1981). In response to this, I attempt to explain each aspect of the research design in more detail in order to provide a clearer understanding of my decision processes.

Data collection methods

Baillie (1995) comments that as ethnographers study holistically, multi-methods are often used to gain a broad perspective. It was proposed therefore to use a variety of methods of data collection within the study, all congruent with the ethnographic approach, including unstructured participatory observation, semi-structured interviews alongside participatory child/young person centred methods. I now provide an outline of these data collection methods.

Unstructured participatory observation

In order to identify the contextual circumstances of children's and young people's experiences of being in hospital, a period of preliminary unstructured participatory observation of children in the ward environment was undertaken. Participant observation is often the method of choice in ethnography. This has led to participant observation in ethnographic terms having been identified as a major data collection technique used in conjunction with interviewing (Robertson and Boyle 1984). However, Carnevale et al (2008) comment that participant observation has been under-utilised within health care settings, possibly due to concerns that children who are unwell are considered extraordinarily vulnerable.

Observing behaviour can be of great value, particularly where small children are involved (Pretzlik 1995). However, I also believed that close involvement in the ward setting would greatly benefit the study. Thus observation was used in the sense described by Robertson and Boyle (1984) in that I concentrated on children's and young people's behaviours as well as observing the ward setting itself. In undertaking this I drew upon my key nursing skills in observation. Throughout I attempted to explore my observations within the interviews with children and young people themselves.

Initially, over a five-month time span, a period of preliminary observation was undertaken. This phase of the study provided the opportunity to observe 30 children over a period of 100 hours. At no time was I involved in the provision of clinical care. However, the observation was participatory through my personal responses and interactions to children and families within the context of the study. This provided a time of re-familiarising myself with both the study setting (in which I had previously worked as a staff nurse) and the staff who work within it. However, this period was invaluable not only in these respects, but also for exploring the context in which care was delivered within this setting and for highlighting the multiplicity of influences which impacted upon children's and young people's experiences. I also became acutely aware of the ways in which children's voices were ignored within the health care setting. Thus, these important issues were highlighted to me as areas to be explored and their significance reviewed in children's and young people's own accounts of being in hospital within the on-going research.

The layout of the ward was an important element in terms of accessing children. Prior to each period of observation, and following discussion with nursing staff where possible, a "bay of children" that were most eligible for inclusion in the study was chosen[11]. This prior discussion helped to ensure that observation was not overly intrusive for those children who were very ill and enabled me to avoid approaching children who did not fall into the age ranges required of the sample. At this time, the purpose of the observation, and the types of activities with which the observation was concerned were explained to the children and parents[12] within that bay in order to request their consent to be involved. Where both children and parents gave their consent, parents were asked to sign a consent form and children an assent form[13]. During this preliminary period of observation I observed only children within the bay settings and not those children being nursed in cubicles. However, at a later stage whilst predominantly my observations took place within the bay areas, I also carried out shorter periods of observations within the playroom and the main ward corridor[14].

The ward layout was a challenge in terms of carrying out observation. The bay areas were quite small and often busy and cluttered, leaving little space to sit or stand and observe. I most often tended to sit by the windows opposite the entrance to the bays as this area tended to offer space where I was less likely to interfere with ward activity and clinical care. At this time, whilst trying to be unobtrusive, I made notes in a small notebook about what I was observing. The ward corridor was another area I wanted to observe, although usually hectic and filled with a range of obstacles such as clinical

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[11] The children and young people approached within the bay were chosen by myself.

[12] The term "parent" is used throughout the text. However, this term is also to include legal guardians of children.

[13] The assent/consent process has been discussed previously within the section headed "Ethical considerations".

[14] The layout of the ward, including the size and location of the bay areas and the reasons for children's allocation to them are explained in Chapter 5.

equipment. As a result I often felt myself to be what I can perhaps best describe as an "awkward object" when carrying out observation in the corridor. This awkward object status arose from the fact that I found that unless I attended to my presence as an observer I could easily have become – and on occasions felt – like an additional piece of clutter or another obstacle to be negototiated by the nurses. To try and ensure that I did observe all areas but that I did not outstay my welcome in any one area I often spent time walking up and down and then retreating to the parents' room for a short while before returning later. I found that I needed space and time to absorb the observations I had made, add to my field notes as well as time to re-gather my focus before starting the next period of observation. I also felt that these breaks provided useful time away not only for me from doing the observation but also for the children and families from being observed.

In order to represent children's experiences more fully, observations were conducted at various time periods including day and evening. This was particularly valuable as time proved to be an interesting factor in terms of who was present with the child and the types of activities that took place. Routines at night time, prior to settling down to sleep, also revealed the extent to which children valued their parents being resident with them, particularly in the younger age groups.

Before beginning the preliminary observation I had some ideas of the types of activities I might be able to observe. These came from both the literature relating to parental participation in care, children's experiences of clinical care and my personal experience of working as a children's nurse. Thus to some degree, these provided a structure to the early observations I conducted and provided confidence to myself as a novice researcher. However, once in the clinical setting I found the amount of information open to me overwhelming and my pre-formulated structure disappeared. Pretzlik (1995) argues that the complexity of the situation is considered and flexibly maintained when an "unstructured" method is employed, that is, when no prior assumptions are made regarding the types of activities to be observed. Such an approach, Polit and Hungler (1991: 324) argue, is particularly valuable for its ability to "get inside a situation", leading to a more complete understanding of its full complexities. Other researchers have reported however that a combination of both unstructured and structured methods can be used to advantage (Dunn 1988). Indeed, Dunn comments that much of the complexity and richness of children's interactions and conversations can be recorded whilst their actions and words can be measured in a pre-determined way. Thus to some extent, I set out with an awareness of the particular behaviours I wished to observe although as the observation went on, I became more receptive to other behaviours.

The observations I recorded included the activities, play and behaviour of children alongside the presence of parents, family members and children's and young people's friends within the ward environment. A variety of events were also observed including feeding, dressing changes, administration of medications, going to theatre and venepuncture. Children's and young people's responses to these events and the reactions and involvement of family members in them were noted. During this time, I documented the choices available to children and young people to influence who was involved in particular care activities.

The observations that I carried out were participatory in that if children, young people or parents approached me I responded to them. I found that this was often the case as many children came and sat with me and involved me in playing games with them or just chatting. Parents also chose to come and start conversations, particularly around their children and their concerns about them and some of the nurses spoke in the corridor about events on the ward that were impacting on their day. However, it is important to note that initially it appeared that people, particularly within a close spaced environment such as a bay, seemed wary of me when I first began my observations leading me to feel as if I was being observed rather than being the observer. However, as described above, this wariness quickly dissipated and activities began to take place again within the bay.

During this preliminary period of observation, I was interested in the potential variety of ways in which family centred care was presented to children and the ways these might impact upon the choices children may make in terms of delivery of care. This led me to observe the nursing admission process. I focused on the interactions between child, family and nurse in relation to discussion about care or negotiation of particular aspects of care. The observation of this particular aspect of hospitalisation is useful in demonstrating the ways in which observation highlighted specific issues which may have been otherwise missed. It is important to note that initially my study aimed to explore children's perceptions of family centred care. However, as I began the preliminary period of observation I began to realise that children, and young people too, had wider experiences to share in relation to being in hospital. As such, I shifted my focus and created my guiding question which was to explore children's and young people's experiences of being in hospital.

I recorded field notes both during and after periods of observation. In recording these I was reflexive and included notes of events and my own personal feelings related to the observations. At a later stage further details were added and the field notes were documented within a reflective journal. In terms of what to record I was guided by Boyden and Ennew (1997: 148):

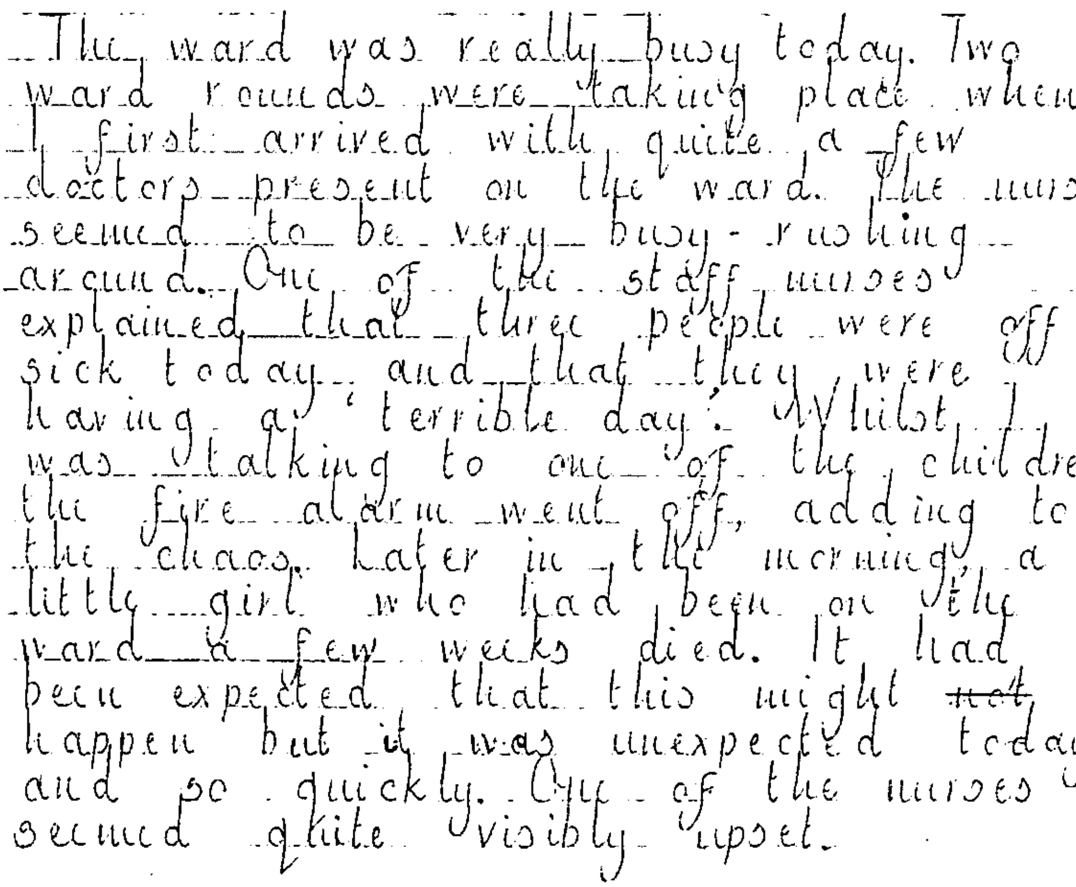
> "Field notes should aim at "thick description", which allows a reader to enter the situation in all its dimensions, rather than superficial, or "thin" description, which simply summarises a few relevant facts".

The list developed and grew over time as I became more experienced and included:

- Initial thoughts, ideas and possible themes to follow up in further observation.
- What was observed including activities, events, incidents, conversations, people present, body language, facial expression, tone of voice, language, who the child looked to, the actual words used, pauses and the surroundings.
- The context in which the observation took place.
- Impressions, feelings and atmosphere.
- Reflections about the significance of what happened.
- Problems and their solutions, issues and questions.

Robertson and Boyle (1984: 45) comment that a reflexive process evolves between the observational and interview data "so that each will tend to suggest additional points of emphasis to the ethnographer". Thus I attempted to document field notes in the ways in which I felt would be valuable and informative when following up insights and potential themes necessary for developing further observation or interview ideas, "as well as for identifying and cross-checking issues during data analysis" (Boyden and Ennew 1997: 98).

In terms of identifying the depth of observation necessary for observational work, I was guided by experienced researchers who shared their in depth knowledge of conducting observations and documenting field notes with me. As a novice to observational work my preliminary field notes were woefully short of the detailed information that such a study demands. These early notes consisted of fairly limited descriptive sentences which failed to provide adequate detail. The guidance proffered by other researchers and the literature was invaluable in gaining confidence in carrying out early periods of observation and writing up field notes. Subsequently the field notes based on my observation were extensive and fed into the interviews where I would ask children and young people about specific observations in order to ascertain their interpretation of events. Observations were documented as field notes which supported data from the interviews, acting as a form of triangulation. The field notes were also used at the analysis stage in order to contextualise children's and young people's experiences. For example, the excerpt from the following field note (see figure 4.2) sets the context in which children and young people received care in hospital.



The ward was really busy today. Two ward rounds were taking place when I first arrived with quite a few doctors present on the ward. The nurse seemed to be very busy - rushing around. One of the staff nurses explained that three people were off sick today and that they were having a 'terrible day'. Whilst I was talking to one of the children the fire alarm went off, adding to the chaos. Later in the morning, a little girl who had been on the ward a few weeks died. It had been expected that this might ~~not~~ happen but it was unexpected today, and so quickly. One of the nurses seemed quite visibly upset.

Figure 4.2 Field note

I have already referred to the pre-conceived ideas I took into the preliminary observation with me. However, I believe that the difficulty I experienced initially in relation to this merits further discussion. Too frequently I found myself looking for behaviours and examples of events described in the literature relating to parental participation in care. As a children's nurse, pre-existing beliefs and values about children's nursing and parental participation were uppermost in my mind. For example, I strongly believed that the emotional support parents were able to offer their child throughout their hospital admission was of the utmost importance. This is a belief clearly demonstrated within the literature. Thus, as I began preliminary observation, I searched for instances that would support the important nature of parents' emotional support. On a personal level, I recognised that observer bias would be reduced if I could focus on issues other than these preconceived ideas. Importantly, as time went on and my confidence increased my reliance on looking for evidence to support the findings of past studies lessened as new themes appeared to emerge.

It is important to highlight that participant observation with children raises particular difficulties and issues. Corsaro (1981) provides one example. In order to gain access to children's perspectives, Corsaro employed the ethnographic technique of participant observation through which he became " ... a participant in the children's culture ... joining in the children's activities whilst not affecting the nature or flow of peer episodes" (Corsaro 1981: 118). Thus:

> "One of the central aims of ethnographies of childhood culture is the suspension of such interpretations. The researcher must attempt to free himself from adult conceptions of children's activities and enter the child's world as both *observer* and *participant*" (Corsaro 1981: 118).

However, the idea that it is possible to suspend or step outside of the cultural meanings assigned to childhood and children has been viewed with scepticism by Alldred (2000: 153) who argues that a more realistic aim might be to attempt to examine the "adult conceptions" alongside, and in relation to, the observations made:

> "In this way one could begin to reflect upon the concepts and processes of the analysis as an ... integration of the methods ... simultaneously with, and as an integral part of, the investigation of the object".

In the initial analysis of the preliminary observational data it is important to note that the interpretations were my own and not those of children and young people. However, once further data collection began, these included children's and young people's own interpretations of observed events and this happened through the interview process.

Semi-structured interviews

After the initial five month period of observation and in order to elicit children's and young people's interpretations of events and their individual experiences of being in hospital, semi-structured interviews were undertaken. These took place alongside on-going observation with those children and young people interviewed having been part of the observations undertaken. I chose to undertake semi-structured rather than unstructured interviews due to my initial status as a novice researcher, believing that having a loose structure to the interview would enable my confidence and expertise to develop. However, right from the first interview, partly as a result of my desire to allow the children and young people to describe the most important elements of their experiences from their own perspectives, I found that they took the lead and tended to structure the issues discussed.

Often the interviews took the form of detailed conversations interspersed with age-appropriate child-centred methods (Balen et al 2000) which had been used successfully within other research studies with children (Hill, Laybourn and Borland 1996, Mahon and Higgins 1995, Clarke, Craig and Glendinning 1993). These new "methodologies of representation" have been developed to enable children to share their experiences through, for example, drawing or stories (Christensen, James and Jenks 2000) and place the voices of children at the centre of the process of research (Barker and Weller 2003).

The interviews were conducted within the ward setting often following a period of observation, in order to allow for the opportunity to discuss observed events with children and young people. I believed that this approach would be useful in both gaining rapport with those involved and in eliciting both their interpretations of events and the meanings a situation had for them. In choosing the ward as the setting for the interviews, I believed that it was important to retain a sense of context. I was guided also by Darbyshire's (1992: 53) comments that the ward setting would "help in keeping the salient aspects of the situation at the forefront of participants' thoughts".

Alongside talking with individual children and young people about observed events, I developed a basic interview schedule for the interviews. This was developed in light of the literature, personal experience and preliminary observation. Of necessity, this changed as data were collected in order to reflect the issues the children themselves were raising. Thus it was imperative to ensure that the schedule was indicative only and refined and sensitised as data collection progressed in order to reflect themes that were emerging from the children themselves.

I attempted to approximate the time span of data collection to the attention span of individuals. Therefore, each interview was sensitive to the individual child/young person and lasted for approximately twenty-five to forty-five minutes. I also took as much care as possible to ensure that each child/young person was well enough to participate in data collection through discussions with the ward staff each time I entered the setting. Time was built into the interviews to allow children or young people to rest or play for a short while if they became bored.

Punch (2002) writes that whilst using appropriate methods is a central concern in any research, in work with children a desire often exists to develop "child friendly" methods that draw upon familiar sources to children or their particular interests. She comments that firstly, adults often assume that children prefer "fun" methods and are more competent at them. Secondly, children often tend to lack experience of adults treating them as equals. Lastly, children as a whole may be more used to the visual and written techniques of data collection because they have experience of these within the school setting. However, Punch makes explicit her view that adults should not assume that this is necessarily the case for all children.

Using methods which are sensitive to children's particular competencies or interests can enable children to feel more at ease with an adult researcher (Punch 2002). This does not mean however that children are incapable of engaging with the methods used in research with adults:

> "The "problem" of adult authority in relation to children may be more acute when the child and the researcher are together on a one-to-one basis. The adoption of more varied and imaginative research methods may make it possible to overcome these problems to some extent; for example, ... interactive research methods such as videos and drawing" (Mahon et al 1996: 149).

Using a range of methods, both innovative and traditional, can help to address some of the ethical and methodological issues in carrying out research with children (Punch 2002). In this study, alongside participant observation and semi-structured interviews, some activity based techniques were used also. These were valuable in preventing boredom and sustaining interest and as Morrow and Richards (1996) report, in preventing biases arising from an over reliance on one method. In planning ways in which to conduct the interviews with children, I recognised that informal conversations with children were more likely to lead to natural discussion (Ireland and Holloway 1996) as many children's conversations occur alongside other activities (Beresford 1997). Within the interview process itself, children were given the opportunity to choose from a selection of methods in order to enable them to express their experiences. These included "playmobil" toy figures structured around a pretend hospital setting in which children were given the opportunity to play with the figures whilst describing their experiences in hospital; a wand in order to make wishes about being in hospital; toys and puppets which the children were able to use as a medium through which to answer questions; and the draw and write technique where children were given the opportunity to draw a picture, or a series of pictures, in response to a particular question or just drawing by itself. Data arising from children's drawing and stories often enabled children and young people to spontaneously shape the research agenda. For example, in explaining her drawing of herself covered in lurid red marks, Daisy,[15] (9) aged 6 years, revealed the way in which she hated having eczema and how it made her feel as if everyone was always looking at her.

Drawing techniques have been identified as an effective method of augmentation with children (Sartain, Clarke and Heyman 2000). The draw and write technique has been used successfully in seeing the world through the eyes of children aged from 6 to 12 years (Gibson et al 2005). Using drawings at the beginning of the interview can decrease anxiety and increase the child's confidence (Walsh 1983), allowing the researcher to discuss the drawing with the child as a means of building rapport. Sartain, Clarke and Heyman (2000) also comment that drawing is a practical way of bringing children into an interview situation and encouraging them to talk about themselves and their experiences. For this reason, drawings were incorporated into the interview where appropriate, particularly as the interview commenced.

As discussed, activity based techniques were also used within the interviews[16]. These related to a variety of aspects that might affect children's experiences in hospital with some incorporating drawing activities if the children themselves wished this. I

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[15] Pseudonyms are used throughout the thesis.

[16] See appendices 13-19.

attempted to use the worksheets as a prompt for children to think about their experiences in hospital if they were unable to think of a response. The worksheets were introduced at the time of gaining assent although I attempted to address the power-differential by empowering children to choose whether or not to complete activities. One of the advantages of using written and visual methods such as these is that it may lessen the unequal power relationship between the adult researcher and the child subject where the child may feel under pressure to respond relatively quickly. Certainly the decision of whether or not to use them very much lay with each individual child and young person, and participants often chose which activities they wanted to complete with others being rejected. As the worksheets were completed at the time of the interview I was able to seek children's and young people's interpretations of their drawings or written responses. The activity worksheets were used as prompts or triggers to conversation and as a way of providing other avenues of discussion within data collection. Thus, where an activity or drawing gave real insight into children's/young people's experiences these were included within the analysis alongside the dialogue around it. For example, the 'Hospital days' activity undertaken by Elena on page 102 supported data around the invasiveness and intrusiveness of treatment and fed into the theme of experiences of the ward routine.

Whilst the worksheets were used within data analysis, detailed analysis of each separate activity was not carried out. However, I undertook thematic analysis of the activities and analysed these alongside the interview transcripts in order to further support the data.

As with the other methods, careful consideration of each child's/young person's individual wishes and needs was paramount in order to address the power imbalance. I found that preferences varied from child to child with some preferring to draw or write and others to talk, play or use a variety. Table 4.2 depicts the activities used, summarising the number of activities each child/young person undertook and the grand total of choice of each method. The table also outlines the total choice of each method by those with acute and chronic illness and by gender.

Table 4.2 Activities used by children and young people

	Being in Hospital makes me feel...	Choices chart	Draw and write	Feelings about hospital	Hospital days	People who are important to me	People who look after me	Drawing	Play mobil/ wand/ puppets	Number of activities completed per child/ young person
	🎈	X or Y	📖	☺ ☹	🕒	👪	🧑‍⚕️	✏	🪄	
Children/young people with acute illness										
2. Anna	X		X	X		X				4
4. Alfie				X			X		X	3
5. Benito								X	X	2
7. Charlie	X			X	X					3
10.Dominic										0
12. Elijah								X		1
14.Florence	X	X		X						3
15.Georgina			X						X	2
16. Grace								X	X	2
18. Harry	X						X			2
21. James					X			X		2
22. Joseph										2
23. Joshua									X	1
24. Katie				X				X		2
26. Libby		X								1
27. Louise										0
31. Malachi								X		1
32. Mia			X	X						2
33. Milly	X	X				X				3
34. Minna										0
35. Oliver										0
36. Olivia				X				X		2
39. Poppy				X				X		2
40. Saira								X		1
43. Stephen										0
45. Yasmeen								X		1
46. Yusuf										0
Total choice of activity (%)	**10.8**	**6.5**	**6.5**	**17.3**	**4.3**	**4.3**	**4.3**	**10**	**10.8**	
Children/young people with chronic illness										
1. Abby	X	X	X		X		X	X	X	7
3. Anya										0
6. Callum								X		1
8. Charlotte										0
9. Daisy			X					X		2
11. Elena					X					1
13. Emily	X			X				X	X	4
17. Hannah										0
19. Isaac								X	X	2
20. Isabelle					X					1
25. Leila										0
29. Lydia										0
30. Maija	X	X					X		X	4
37. Oscar								X		1
38. Paolo								X		1
41. Samuel										0
42. Sarah	X		X	X					X	4
44. Violet			X	X				X	X	4
Total choice of activity (%)	**8.6**	**4.3**	**8.6**	**6.5**	**6.5**	**0**	**4.3**	**17.3**	**13**	
Grand total choice of activity (%)	**19.5**	**30**	**15.2**	**23.9**	**10.8**	**4.3**	**8.6**	**39.1**	**23.9**	
Total gender: Male (%) Female (%)	**4.3 15.2**	**0 10.8**	**0 15.2**	**4.3 19.5**	**4.3 6.5**	**0 4.3**	**4.3 4.3**	**17.3 21.7**	**8.6 15.2**	

Children also commented upon the activity sheets and the ways in which they could be improved. For example, when completing the "Being in hospital makes me feel" activity which depicts a person holding balloons with spaces for children to write their feelings, Emily (13) commented that there should be some balloons flying away from the person to allow children to feel that their negative feelings were being blown away.

The play activities I used included not only the "playmobil" and other toys I took into the interviews with me but also activities triggered by the children. These ranged from the young person demonstrating his array of card tricks to me halfway through the interview, playing ball with a young sibling of another respondent and posing questions both to the Emu puppet of one child and to another participant while she was standing on her head. Whilst these activities are not widely reported in the literature, they reflect the particular flexibility that researchers working with children require.

Faux, Walsh and Deatrick (1988) comment that children of different ages present different challenges to the interviewer. This is clearly of consequence where a study involves children and young people of a wide range of age groups. Moreover, as these authors discuss, language and cognitive maturity often vary widely in children of approximately the same age. Thus interviews with children demand flexibility and adaptation of the interview technique and questions to each individual child and young person. Indeed, the methods the children themselves chose to express their experiences were wide-ranging and did not always relate to the age ranges I had loosely attributed to each method. For instance, on one occasion a ten year old chose to play with the playmobil and other toys I had taken into the interview with me. However, another ten year old wished to give a recorded face-to-face verbal account of her experiences.

Some issues and strategies that need to be considered when conducting the interview include the adult-child relationship, data inconsistency, children's lack of familiarity with the interview situation and the limited attention span of children (Faux, Walsh and Deatrick 1988). I will next outline the measures that I took to address these important issues.

Faux, Walsh and Deatrick (1988) advocate allowing children to tell their own stories uninterrupted rather than by asking many different questions. These authors suggest that this approach ensures data is credible as children give information which is meaningful to them. Thus I encouraged the participants, particularly younger children, to share their stories and experiences through drawings and play, with questioning techniques being used to clarify and supplement data rather than acting as the main method of data collection. In order to clarify inconsistencies in children's responses, reflective techniques, paraphrasing to check what had been said (see Waltz, Strickland and Lenz 1984) and probing for specific examples (see Faux, Walsh and Deatrick 1988) were used. Counter suggestion (or repeating the same question in alternate ways) has also been advocated as a method of checking both the firmness of a belief and response validity by Faux, Walsh and Deatrick (1988). Again, this was used where appropriate.

In recognition of the unfamiliarity of the interview situation, the importance of opening questions in setting the tone of the interview and allowing children and young people to know what is expected of them has been noted (Horstman et al 2008, Rich 1968, Yarrow 1960). Faux, Walsh and Deatrick (1988: 191) demonstrate the need for questions to be ordered from the "non-threatening" to the more "threatening" to allow time to build rapport and trust. These authors also comment on the usefulness of starting with more general questions and proceeding to more specific ones in order to allow children and young people to state their frame of reference and respond in ways that are meaningful to them. In order to respond appropriately to emotional reactions during the interview, the depth of questioning was tailored within individual interviews to allow children and young people to withhold information whenever they so wished. Indeed at times I was humbled by the depth of experiences the participants shared with me. These included instances of bullying where obvious emotional trauma had been experienced, to traumatic experiences within the hospital environment itself. In some way I feel that these responses indicate the rapport that had developed between myself and the participants. However, there are difficulties in building up rapport in a short space of time, particularly when the respondents were unwell and in an unfamiliar environment. Attempting to gain rapport with the children took time as data within the field notes indicates:

> [We talked for approximately one hour prior to the interview about pets. This ice-breaker was very important as when I first entered the cubicle Emily appeared to be looking tired and was taking her medicine. I introduced myself and briefly explained the study to Emily, her mum and sister and felt intuitively that Emily might not want to participate as she seemed quite quiet and a little withdrawn, so I offered to come back later. However, mum was very keen for me to stay saying that Emily would be fine as soon as she had taken her medicine which she dislikes intensely and that participating would take her mind off things. I decided to give out the information sheets which mum and sibling read whilst Emily was still taking her medicine, then explained the study verbally to Emily once she'd finished giving her the opportunity to learn about the project before she read through the information sheet. This led to a long discussion about pets during which everyone, but especially Emily and her sister, became really animated, happy and talkative. After this Emily was very willing to be involved and commented afterwards about how much she had enjoyed herself] (Fieldnote).

Following the interviews, children and young people were given a certificate[17] thanking them for their participation.

Analysis of the data

Since the primary goal of ethnography is richness of data leading to descriptive analysis, Robertson and Boyle (1984: 47) comment that the ethnographer must "strive to cover the full range of the phenomena so that the resulting interpretation will entail meaningful understanding of the culture". The complexities that abound within such an analysis are well documented in the literature. Geertz (1974) comments for example, that the ethnographer is faced with a multitude of complex conceptual structures, with many superimposed onto or knotted into one another, which are irregular, inexplicit and strange and must be grasped and then rendered.

In this next section I describe the data analysis process and the development of the analysis.

Data analysis process and development

Firstly, the interview transcripts and activities undertaken by children and young people as part of the data collection were scan read to sensitise myself to potential relevant ideas and themes. This served to develop a sensitivity or awareness of possibilities within the data. I saw this as a time in which I could immerse myself in the transcripts and thus during this stage I read the transcripts between three to four times. During this

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[17] See appendices 20-22.

reading I noted those codes, such as "feeling lonely", "miss my mum", and "wish to be at home", that appeared to be emerging. These codes were words, phrases, sentences or paragraphs that embodied ideas. Each occurrence of a code in the data was then identified as described by Woods, Priest and Roberts (2002). During a further reading of the transcripts, the codes were reviewed and amended as new data emerged.

It is perhaps useful at this stage to describe this process of coding. Following my re-reading of the transcripts I began to place examples identified in the text within one or more open codes. During this stage, I made notes alongside the margin of the transcripts as personal reminders of potential themes or ideas that appeared to be emerging. I also began to identify patterns in the data by writing memos where I felt that one or more codes were closely related. At this time I jotted down these potential ideas and themes into my field diary so that I would be aware to follow up these links within on-going data collection. For example, as data collection progressed I began to question whether a link was emerging in terms of the ways in which parents' participation in care enabled children and young people to influence care delivery by professionals. In order to explore this, I took special care to highlight the ways in which parents' participation in care was proposed to children and their parents' during on-going observation. This led me to incorporate the nursing admission process into data collection in order to examine more closely discussions regarding parents' participation and the negotiation of care delivery.

Data collection and analysis were iterative with interview topics supplemented with emerging issues as the study progressed, as advocated by Swallow (2008). Due to this, coding became more detailed as data collection progressed, resulting in amendments being made as the on-going review of the codes continued. In ethnographic terms, Field and Morse (1985) suggest that the on-going analysis which takes place as fieldwork progresses leads to the development of propositions which are tested through further data gathering and analysis.

I carried out the process of reading over the transcripts, initial coding, cutting and filing, concurrently with on-going data collection[18]. This concurrent data analysis is recommended in qualitative analysis because each process can enhance the other. In

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[18] Activity sheets and drawings from children and young people were also included.

order to organise the codes these were grouped into categories. During initial analysis, many categories such as "loneliness", "people missed" and "normality" were generated from a wide range of areas. However, as categories began to emerge, on-going data collection further developed and saturated these categories. I believe that this approach enabled analysis to deepen and data collection to become more insightful as it proceeded. This has been confirmed by other writers such as Wainwright (1994) who have commented that returning to segments of data as the study progresses leads to concepts becoming enriched and more elaborate.

Predominantly researchers advocate analysis alongside continuing data collection in order to allow for insights from interviews and participatory observation to be explored in subsequent data collection in order to confirm or refute developing understanding. Callery (1995) comments that this approach can also prove beneficial in giving assurance of the quality of data collection methods. I believed that a constant appraisal of the on-going data collection methods I used with children and young people would be of immense value.

During a later re-reading of the transcripts, which I deliberately delayed for a period, the codes were reviewed and amended. A more mechanical aspect of this process of data analysis was that I duplicated copies of the field notes and transcripts, using the second copy to cut up examples of particular codes. These were then pasted onto A4 paper and filed under individual code headings. I left a complete copy of the transcripts un-marked to preserve in case I believed it important to re-read the full notes entirely afresh at a later stage.

The categories were next grouped into themes which possessed distinct properties. Wainwright (1994) proposes that these themes should be sufficiently broad, mutually exclusive and allow inclusion of all coded data from the field notes. Once this stage was commenced, I began to question and contemplate these emerging themes more rigorously. At this time, I sought to identify themes and patterns, similarities and differences, comments and particular events within the data, which appeared important to children's and young people's experiences. For example, ongoing observation and interviews with children and young people revealed that categories around parents, for example, "need for parents", "importance of parents' presence", "roles undertaken by parents" were dependent upon, for example, the age of children, their past experience of being in hospital and chronicity of illness.

Glaser (1978) writes that the explanation as to what is happening in the data from preliminary codes is learned from careful data analysis and the conceptual grouping into themes. During this stage I made analytical notes. Most often I used these notes as a way in which to explain my thoughts as the codes and themes developed. However, at this time I also jotted down any questions or ideas related to the analysis which came to mind. Reading around the literature surrounding data analysis heightened my awareness of the importance of this step. Wainwright (1994) describes that careful and detailed description of this stage of the analysis ensures that the eventual interpretations may be traced back to concrete empirical data culled from the transcripts. Therefore, the notes I made at this time were more lengthy and discursive than those written in the preceding steps. Typically these entries ran to between 10-20 lines.

During the analytic process as a whole, writing memos was an important technique in keeping a record of how themes and issues were developing. These analytical and process memos were used to document my changing views of the data and to include personal, reflexive descriptions of my ongoing attempts to interpret the data, for example, see appendix 23. Thus these memos formed the foundations for the interpretation of the qualitative data.

As the analysis progressed some of the early codes were either recast or discarded. It was at this time that the benefit of initial immersion in the data became evident. Thus, even though data were fractured and placed within separate codes, it was possible to recall the context in which the data were collected. Once the data were collected the various stages of analysis continued concurrently but coded data were considered at a theoretical level by comparing emerging patterns with the literature in order to explain the data in light of, or departure from, existing theory. For example, once the overarching theme of "disruption" was identified this was compared with the existing literature in order to develop this further by examining literature around disruption in social worlds (Hall and Stacey 1979), disruption caused by illness (Levealahti, Tishelman and Ohlen 2007) and illness as a disruptive experience (Bury 1982). Whilst the literature offered some insights into how this theme could be developed further, it was recognised that children's and young people's accounts were describing disruption in a sense not depicted within the existing theory. After data collection was completed, the data contained within this theme was reviewed and explored within the literature. This resulted in an examination of the literature surrounding disruption, allowing concurrence and departure to be identified between the literature and the data.

The interpretation of qualitative data

The interpretation of qualitative data provides further challenges when undertaking research with children (Bricher 1999). This is summarised by Mayall (1996) who asks if it is ever possible to convey children's experiences if you are not a child yourself? Punch (2002) argues that the choice of which data to include and the interpretation of that data is generally in the power of the adult researcher. As adults, we are limited by our tendency to process children's words through our own view of the world (Fine and Sandstrom 1988). Indeed, Coad and Evans (2008) argue that children's perspectives have been filtered through the interpretations of adult researchers within conventional research methodologies. Other writers recognise that the method of enquiry is inextricably bound to the interpretation, and to be effective, this must recognise the culture of childhood and of the particular child (Bricher 1999). As McGurk and Glachan (1988) write, if we are able to recognise that there is a separate culture in which children exist, then it is easy to see how one can have adult-centric interpretations of childhood. Therefore, the real question is whether adults have the knowledge to make accurate representations of the child's perspective. Adult-centrism can be seen to operate at both an individual level whereby adults tend to interpret the actions and utterances of children as immature versions of their own speech and behaviour (Bruner, Jolly and Sylva 1976), and at a cultural level too:

> "For adult-dominated culture, language is, "by definition", reflective and productive of adult power, status and authority. Since the whole frame of reference is adult-centred, it is difficult to see to what extent children could, as ethnographic subjects, present "their own" account of their worlds. Furthermore, it could be argued that children are having to render themselves meaningful in adult-centred terms, and explain themselves convincingly to those in power over them. Seen in this light, children's interviews, because they entail the requirement to make sense for adults, might not necessarily be empowering occasions for children. The idea that any ethnographic subjects are free to present their own meanings in any radical sense neglects the ways in which the dominant culture provides hegemonic meanings" (Alldred 2000: 154).

Bricher (1999) argues that it may be that no adult can fully interpret children's data. As Mayall (1994) summarises, the representation of children's views may be only partially accurate and may be mediated by the adult researcher's concerns and interests. However, as she continues, attempts should be made to understand the child's perspectives, even though interpretation of data is inherently one sided (Bricher 1999). Thus, while data collection consists of both children and adults, predominantly it is the adults who conduct the interpretation (Ritala-Koskinen 1994). Clearly, problems exist with this. In fact:

> "Recognising the fact that in providing a research voice for a particular group we may simultaneously reinforce their construction as Other and concurrently our own perspective or the dominant cultural perspective as central, prevents us from naively assuming that our work is bound to be liberatory" (Alldred 2000: 154).

However, this is a dilemma which all researchers carrying out studies with children and young people must confront. It would appear that no one way exists which can adequately address this issue. One way of "validating" adult interpretations of children's responses is by asking the children themselves to be involved in the data analysis process (Coad and Evans 2008). However, for a study such as this which was conducted over several years, the difficulties in tracing a potentially moving population of children would be immense. Furthermore, children may not wish to be involved in this interpretation or, as Mayall (1996) comments, have grown out of their stated views. Thus, my own personal response to this dilemma is to use direct quotations from children and young people themselves in order to allow others to better follow my own reflexive, interpretive analysis. Quotations from children and young people within the research findings will also assist in my attempts to give children and young people "a voice" and ensure that their accounts are not rendered invisible.

Worthwhileness and credibility

Ethnographic studies must address the fundamental problems of reactivity and subjectivity if they are to be deemed "trustworthy". As Long (1984: 96) notes:

> "For how does one know whether the researcher's observations and analyses are not selective and biased?"

However, as Darbyshire (1992: 63) comments, this is not to say that "the specific criteria devised to evaluate more positivist or quantitative work can be applied to qualitative work". Indeed, debates concerning rigour and validity in relation to qualitative research have taken place over recent times. Webb (1993: 420) argues that whilst some qualitative researchers believe that "traditional definitions of concepts such as validity and reliability should be modified and adapted so that they can be readily understood and accepted by those working with "traditional" definitions used in positivist approaches", others however, take an opposing view and argue that, "since qualitative research operates within a different paradigm, there is no reason to rely on traditional concepts related to rigour and validity". Instead, as Marshall (1986) comments, qualitative approaches require different ways of conceptualising and evaluating rigour.

The criteria for the reliability and validity of studies as proposed by the positivist tradition appear to be inappropriate for an interpretive approach to research with Callery (1995) commenting that the concept of reliability does not sit comfortably with ethnography. However, clearly it is unsatisfactory to criticise positivist approaches to rigour without identifying a more appropriate approach. Whilst there are other ways of addressing rigour in qualitative research (see Maggs-Rapport 2001) in the next part of this section, I move onto describe the approaches used to address research rigour within my study.

Research rigour

Acker, Barry and Esseveld (1983), in an examination of ways to ensure objectivity and truth in feminist research, highlight their concerns in evaluating whether research is "worthwhile" and "adequate" rather than "valid". From the perspective of these authors, worthwhileness is concerned with the degree to which the goal of the research is achieved. Adequacy, meanwhile, is assessed using three criteria which are: whether the voices of participants are heard in research reports; whether the role of the investigator is theorised as well as that of those investigated and whether the analysis reveals the social relations which lie behind the lives of those being studied. Webb (1993: 421) writes also of other researchers who prefer the term "adequacy" to encompass reliability and validity. These include Hall and Stevens (1991) who comment that results are accurate if analytic interpretations fairly and accurately reflect the phenomena that investigators claim to represent.

Other writers however, (see Ryan-Nicholls and Will 2009) argue that the wide and diverse range of qualitative methods render the use of one specific set of criteria to evaluate rigour insufficient. It has been suggested that eliminating bias is impossible (Hall and Stevens 1991) and inappropriate in "passionate scholarship" (Du Bois 1983). Thus a reflexive approach is essential in order to:

> "make explicit the participation of the researcher in the generation of knowledge, adding to the accuracy and relevance of results" (Webb 1993: 421).

Credibility is evaluated by how much confidence others have in the data (Denzin and Lincoln 1994) and whether participants' experiences have been faithfully represented (Webb 1993). In relation to this, Hall and Stevens (1991) emphasise the "believability" of accounts in the eyes of other researchers. To ensure believability, researchers should ask other researchers:

> "to verify the comprehensiveness of literature reviews, the "effectiveness" of data collection techniques, the "comprehensibility" of descriptions, the "inclusivity of samples and the logic of the arguments" (Webb 1993: 421).

The degree of rapport established between researchers and researched, the internal coherence or unity of the report and the complexity of the analysis should be assessed (Hall and Stevens 1991). Webb (1993: 421) writes that, "the latter point relates to how well the complex nature of participants' everyday lives and reality is reflected in the report. Evidence of both consensus and divergence should also be sought, and there should be a discussion of negative cases and alternative explanations". This is advocated also by Mays and Pope (2000). Special mention is also given to the importance of researchers' documentation of how they have attempted to reduce power inequalities within research relationships. Hall and Stevens (1991) advocate also for the experiences of participants to be reported in their own words.

Hammersley (1998) argues that prolonged sampling in the field can enhance credibility in ethnographic research. Being within the study setting for a prolonged period of time provided the opportunity to observe phenomenon occurring repeatedly. Furthermore, contact with children and young people meant that it was possible to confirm their interpretations of observed events and elicit the meanings of their comments or drawings, an approach recommended by Barbour (2001).

Application of worthwhileness and credibility through a reflexive approach

To increase the plausibility or rigour of ethnographic research, Pellatt (2003) advocates the inclusion of a reflexive approach throughout the research. Reflexivity can be described as a "style of research that makes clear the researcher's own beliefs and objectives" (Gilbert 2008: 512). Peshkin (1988) comments that the reflective, questioning process of qualitative investigation actively observes, evaluates and counterbalances the influences that bias may have on data collection, analysis or the drawing of conclusions. Within ethnographic studies, where a large part of data collection focuses upon observation, certain difficulties exist. One major problem within observational work is the effect that the observer has on the behaviours of those being observed. Indeed, Hertz (1997) comments that reflexivity enables the researcher to minimise the effect he has on the research. However, whilst the literature highlights some of the ways in which researchers have attempted to ensure their presence interrupts the study setting as little as possible (Pretzlik 1995), it appears that this is difficult to achieve in practice.

In order to respond to this within the data collection and analytic stages, it is essential for the ethnographer to record not only their personal observations of the participants' view of the world, but to reflect also on their own actions and the potential impact this may have on those observed. This includes identifying the processes by which data and findings were produced in the final report. This "reflexive" approach thus "provides the means for attempting to evaluate the threats of reactivity and subjectivity" (Long 1984: 96).

Long (1984) comments that a reflexive account must acknowledge the researcher's continual monitoring of his/her own actions and interpretations of events as the research progresses alongside data collection in order to provide a basis for later methodological assessment. Similarly, Pellatt (2003) draws attention to the need for on-going self critique by the researcher throughout. Long (1984) argues that such reflections must be made clear to the reader by providing an account of the researcher's role in the research process, the data generation, its analysis and interpretation. Thus through reflexivity, the ethnographer reanalyses the data with a view to checking and possibly developing alternative interpretations, particularly in relation to those which point to the possible impact of the researcher.

Throughout the study I have applied a reflexive approach. In this I am guided by the work of Hammersley and Atkinson (2002, 1995) who comment that descriptive and interpretive adequacy may be sought through continuous reflexivity. During concurrent data collection and analysis I attempted to consistently reflect upon emerging themes, events, feelings, similarities and discrepancies within the data that appeared to be of importance to children. I recorded a sustained, reflective dialogue within field notes in order to record how my thoughts were developing. During data collection, I consistently reflected upon the research methods used with children and young people in order to ensure that I was eliciting individual interpretations of observed events and direct experiences.

Throughout the process of analysis, I sought to establish credibility by embedding the analysis in the descriptions of the children and young people to ensure that analysis was grounded in the data. Worthwhileness and credibility are also provided by the constant comparative method in which alternative interpretations were sought in order to guide the development of the analysis.

In addressing the issue of the deviant case within qualitative analysis, Callery (1995: 107) comments that:

> "The crucial question for the reader of a piece of qualitative analysis is the fate of the deviant case during the development of an explanation by the analyst. The handling of cases that do not fit the developing explanation is central because it can either undermine or enhance the credibility of the study. The worst suspicion that a reader can have is that the analyst has suppressed the cases which did not support the explanation".

I ascribe to Callery's comments that deviant cases may be seen as "an opportunity to enrich the explanation rather than as a threat to the integrity of the explanation". I recognise also, that a more encompassing and thorough analysis can be produced by accommodating and explaining deviant cases within the final analysis. Thus, in my management of data analysis, I include deviant cases and attempt to explain these within the richness of the data gained from children and young people.

Within this thesis I make frequent use of quoted material from children and young people in order to illustrate their own insights and perspectives. Finally, throughout the writing up of the study I have documented my own reflections at each stage of the research in order to enable readers to identify my thoughts and feelings within the research process.

Summary

In summary, in this chapter I have outlined the ethical principles that guided this study and the selection of the research participants. Finally I have outlined the data collection methods used and discussed the issues around using these particular methods in research with children and young people. This has been followed by a description of the process of data analysis. In the next chapter I describe the ward setting in order to provide further context for the study and start to establish my use of Bronfenbrenner.

CHAPTER 5:
THE STUDY SETTING AND THE PARTICIPANTS

CHAPTER 5: THE STUDY SETTING AND THE PARTICIPANTS

> "It's a big place (ward) in a big, big hospital and because it's so big you have to run everywhere, otherwise you wouldn't get to where you were going" (Elijah, (12) aged 8 years).

Introduction

In this chapter I start to present my findings by outlining the context of the study setting including the hospital setting, the ward and staff, and daily life in the ward in which the study was set. Finally, I describe the children and young people who participated within the study. In this description I present a rich description of the fabric of the setting to explain the context of the study rather than an analysis of the socio-political elements affecting the system.

The context of the setting

The study was conducted in a children's hospital in a large city in the North of England. The hospital was served by public transport including buses and trams and was accessible also by car although parking around the hospital was extremely difficult. The hospital consisted of a variety of buildings, both old and new, some being built in the early 1900's and others more recently in the late 1990's. The building itself, particularly the older section, could appear quite imposing for children and young people as Joshua, (23) aged 12 years, commented:

> "When I first saw it (hospital) I thought … it looks dead scary, especially that old bit. Like one of those places in medieval times where people used to get tortured".

The hospital provided many specialist services for children and young people culminating in its status as a regional and supra-regional centre for children's services. As a result of the expertise the hospital was able to offer, children and young people were often referred from a wide geographical area, as well as the "local children" from the city in which the hospital was based. Reflecting the diverse population within the city in which it was based, the hospital provided care to children and young people from a number of minority ethnic groups.

Both Accident and Emergency and Intensive Care facilities were available within the hospital site. For those children and young people requiring consultation with hospital staff but not necessarily admission, a wide variety of specialist out-patient clinics were also available. Due to the specialist facilities provided, some children and young people travelled distances of more than 200 miles to attend the hospital.

The hospital setting

Upon entering the hospital children and young people came into the main reception. All the areas that children and young people visited were decorated with brightly coloured designs on the walls and floors, although it appeared that these decorations did not always appeal to the children and young people themselves, as Lydia's (29) quote reveals:

> "You'd think that they'd never seen an older child in their lives the way that this hospital's been created in the children's bit" (Lydia, aged 10 years).

Accessing the study ward from the main reception led children and young people through a maze of corridors from the more recently renovated part of the hospital into the older building. From this point, the entrance to the ward was directly three floors above and could be accessed either by lift or by stairs.

The ward and staff

Children and young people entered the ward through doors opening directly onto a central corridor. For security reasons access to the ward was via an intercom system. As can be seen in figure 5.1, the ward consisted of twenty beds arranged in two four bedded bays, a six bedded bay and six cubicles, although at the time of data collection the ward was open to only eighteen beds. All the bedded areas could be entered from the corridor running the length of the ward. Most children and young people admitted to the ward were nursed in one of the bay areas unless isolation was important for the child or young person or for others. The bays and cubicles were all painted in primary colours with a clown border running around the walls.

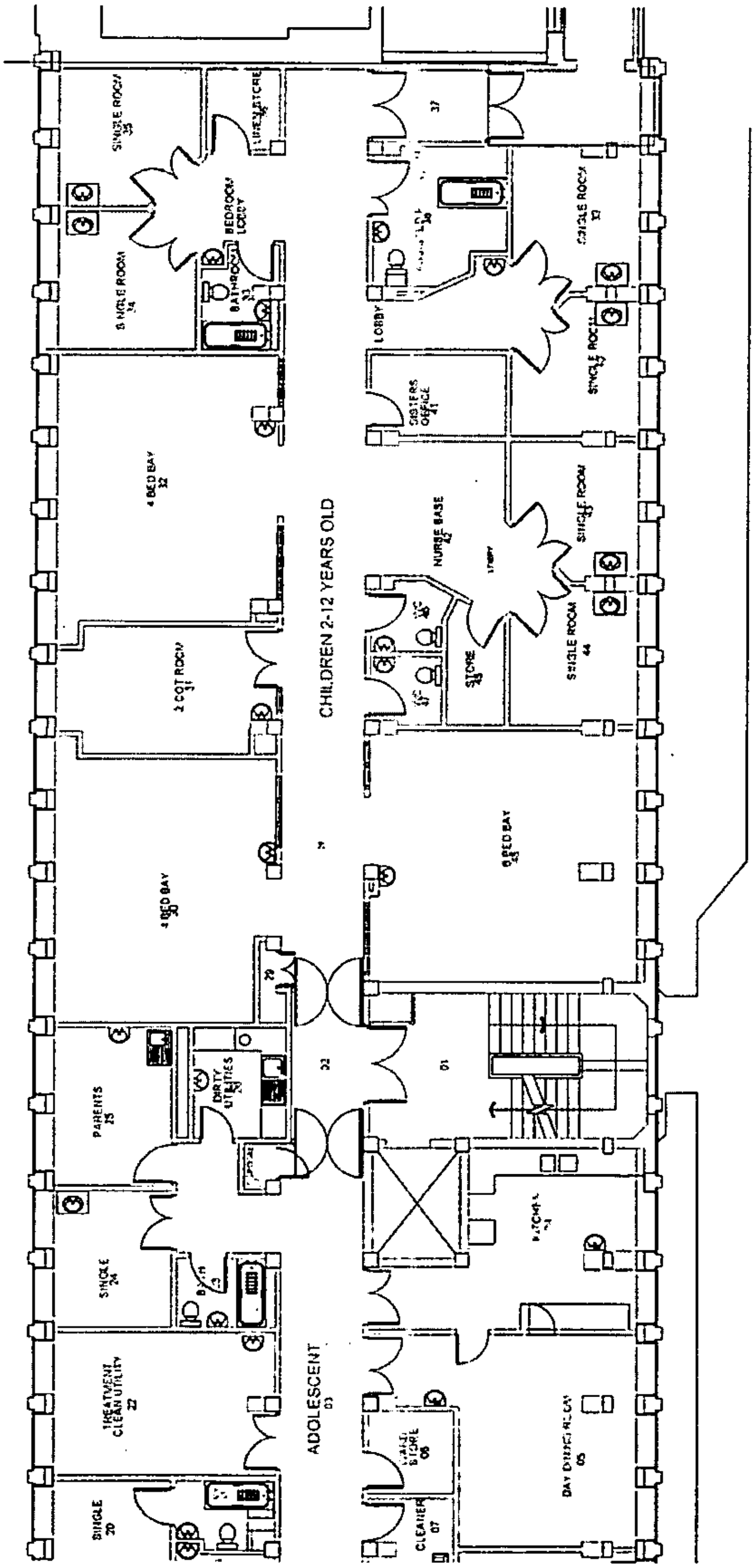

Figure 5.1 Ward layout

Each child and young person had their own bed space consisting of a bed and locker, with space along one side for a fold-up camp bed for parents. Often pieces of medical equipment necessary to children's and young people's treatment such as infusion pumps, oxygen saturation monitors and feed pumps were around bed spaces, resulting in them being more "medical spaces" rather than individual places for children and young people as Oscar's (37) picture[19] (see figure 5.2) reveals.

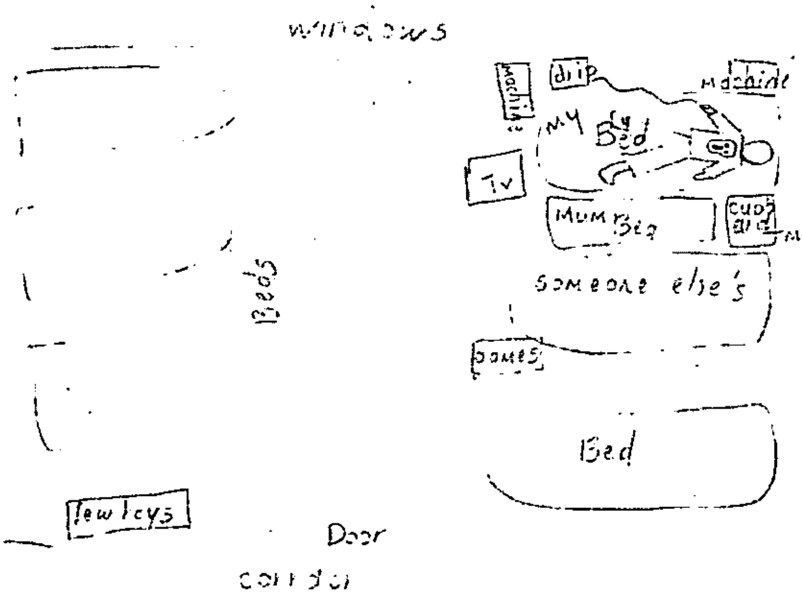

Figure 5.2 Drawing by Oscar

Two toilets and two bathrooms were available for children's and young people's use. The ward also contained a treatment room located between the two four bedded bays. This room had multiple functions as an area for both examining children and young people and undertaking clinical procedures such as taking bloods or changing dressings. Located in the centre of the ward was the nurses' base. This and the nurses' office were the focal points for professionals gathering and exchanging information about children and young people.

As can be seen from figure 5.1, whilst all of the above mentioned spaces were entered from the right side of the stairwell, other ward areas such as the kitchen, playroom and parents' room were based to the left of the stairs. Thus accessing these spaces from

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[19] The children's and young people's drawings and activity sheets are not representative of the original size. However, this does not detract from them or reflect that greater or lesser importance has been attached to them.

children's and young people's bed areas necessitated entry through two sets of fire doors and as such were deemed "out of bounds". Close to the kitchen, separate coffee rooms for parents and nursing staff existed. When the play specialist was on duty children and young people were able to access the playroom, either to play or to borrow games or art materials to take to their bed space. Close to the playroom was a space intended for teenagers.

Children and young people came into contact with a variety of professionals during their hospital stay. These included nursing and medical staff, physiotherapists, dieticians and both nursing and medical students. Other members of staff encountered by the children and young people included teachers, domestic staff and play specialists. In direct contrast to many of the other professionals that the children and young people met, members of the nursing staff were constantly based on the ward. In terms of qualified nurses the ward was staffed by Registered Children's Nurses on either Part 8 or 15 of the nursing register. A table of the numbers and grades of nursing staff are displayed in appendix 24. The experience of the nurses was varied in terms of length of time since qualification and past experience of nursing children. Alongside the permanent members of the nursing team, the ward provided placements to nursing students from both pre and post-registration courses.

Generally between six to nine members of the nursing team were present on the ward during each day. These included a variable skill mix of a sister, between two to three staff nurses, two health care assistants and often two to three student nurses. At night time fewer members of staff were present. In the main, these tended to be three to four members of nursing staff. As the ward was frequently busy and short of staff, often children and young people were cared for by agency nurses who worked on an ad hoc basis.

Daily life in the ward

For children and young people daily life in the ward appeared to be structured around routine events associated with treatment, such as the taking of bloods, the administration of medications and ward rounds, and those based around basic needs such as eating and meeting hygiene needs. Here I describe the daily routine that I observed within the study setting in order to provide a background to children's and young people's experiences.

The day began at 6.00am for many of the children and young people when they were woken by nursing staff recording their vital signs. For some children and young people medications were also given at this time. From 7.00 to 7.30am the night nurses handed over to the day staff.

From 7.45am breakfast was available. By 8.00am the qualified nurses began to administer any medications due at this time. At 8.30am the ward rounds began. At this time consultants, other medical staff and occasionally physiotherapists and dieticians visited the children and young people under their care.

From 8.30am the physiotherapists arrived on the ward and began to treat those children and young people requiring treatment. For children and young people with cystic fibrosis, breakfast was often delayed until they had been treated by the physiotherapist. By 9.30 the nursing staff began to administer medications and record vital signs as previously. At approximately 10.00 am the school teacher arrived on the ward. Teacher support was provided for children and young people from the ages of 5 to 16 years.

From 10.15 am onwards, children and young people without resident parents or families were assisted in getting washed and dressed by nursing staff. Lunch was served at 12.00. Qualified nurses also administered any medications due at this time.

By 1.00pm the school teacher returned to the ward to collect set work from children and young people and to work with those not seen during the morning. 2.00pm saw the qualified nurses administering medications and recording vital signs. Between 3.00 and 5.00 pm was generally leisure time for children and young people when they participated in activities such as watching television, DVD's or drawing. Family and friends also tended to visit at these times.

Tea was served at 5.00pm. Just before 6.00pm the nurses began to administer medications and to record children's and young people's vital signs. 6.30pm onwards was again leisure time for children and young people and a time when visitors again attended the ward.

By 7.00pm the nursing staff working the night shift had arrived onto the ward and took handover. From 7.30pm lights were turned down in those areas where babies and young children were being cared for. At 10.00 pm, medications were administered by nursing staff with vital signs also being recorded. At 10.30pm the lights were turned down and children settled down with resident parents tending to go to bed by 11.00pm.

Overnight, children and young people were most often disturbed to receive medications with vital signs occasionally being recorded at 2.00am. From this time children and young people were then generally left to sleep until the nurses' rounds began again at 6.00am.

The routine was established and tended to be inflexible regardless of children's and young people's experiences and individual needs and is reflected in their accounts in Chapters 6 to 8.

The children and young people

Due to the specialist facilities offered by the hospital, diversity was reflected in the wide range of children and young people with both acute and chronic conditions and illnesses being admitted. However, the regional facilities provided by the hospital resulted also in the admission of children and young people requiring highly specialist care and treatment. Others, with chronic conditions such as cystic fibrosis, difficult to manage diabetes mellitus and some metabolic conditions, received on-going treatment from the hospital due to the complex nature of their illness. The boundaries between acute and chronic illness were not always clearly defined with some children and young people with chronic diseases requiring admission due to an unrelated acute illness or whilst suffering from an acute phase related to their long-term disease. Thus, children and young people receiving protracted treatments were cared for alongside those who were both acutely and seriously ill.

As described in Chapter 4, children and young people aged between 5 to 16 years with a range of both acute and chronic illnesses participated in the study. Of these, some also had physical and learning disabilities. The children and young people within the study came from a number of minority ethnic groups, reflecting the diversity of cultural backgrounds present both within the city and population which the hospital served. Whilst the majority of children and young people within the ward were admitted and discharged within a matter of days, others with chronic illnesses and complex needs often remained on the ward for much longer periods of time. As a consequence, many of the children and young people, particularly those who were admitted for long periods of time and those with chronic illnesses requiring frequent admissions, were well known to the ward staff. For those children and young people who participated in the study however, length of stay at the time of interviewing ranged from the first to twelfth day although some had experienced recent admissions to the ward lasting for between two to twelve weeks.

The following short summaries describe some of the children and young people who participated in the study. Whilst I have biographical data on all those who participated, these are chosen in particular to reflect the diversity of ages and both acute and chronic conditions. These children and young people also have wider hospital experiences having undergone treatment in Accident and Emergency, Intensive Care and theatre.

Poppy

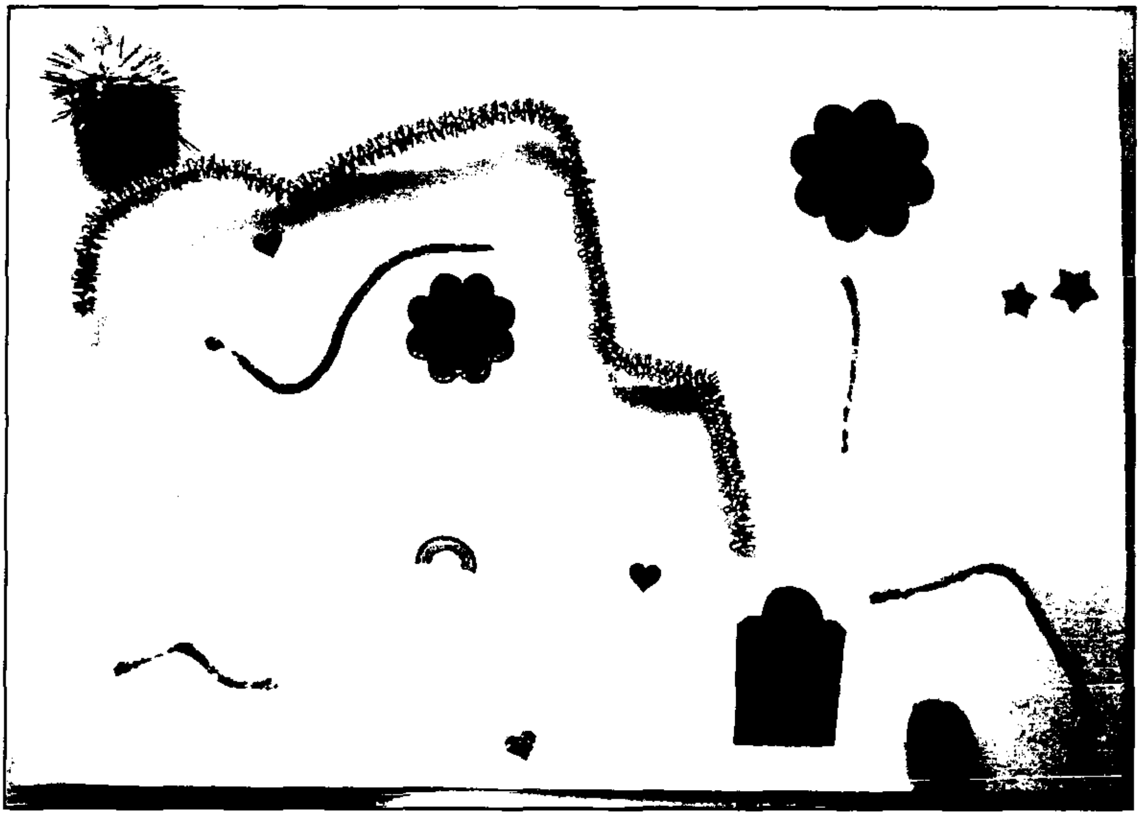


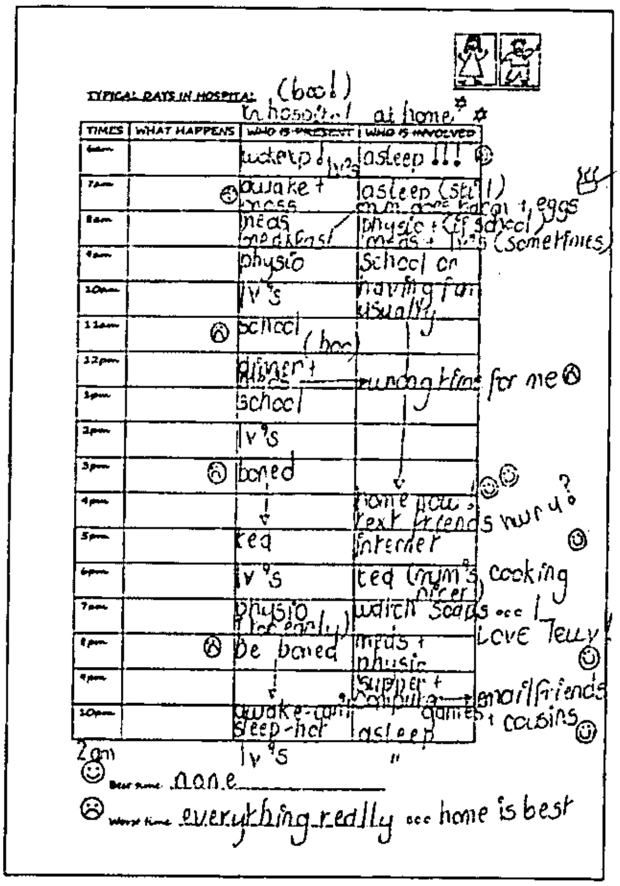
Figure 5.3 Drawing by Poppy

Poppy, (39) aged 6 years, was admitted to the ward as an acute local emergency admission from Accident and Emergency after having a convulsion. This was her first admission to hospital. Poppy's account reflects upon receiving treatment in Accident and Emergency:

> "I felt poorly and then I woke up in a scary room that wasn't here (on ward) but downstairs (in Accident and Emergency). There were lots of people I didn't know and I didn't like it but they got my mum. They gave me a needle that hurt and medicine that made me feel like I was on a roundabout (dizzy). And it was loud because lots of people were shouting".

Elena

Elena, (11) aged 14 years, has cystic fibrosis and was admitted as a list admission for a procedure as part of the long term management of her disease. She has been in hospital frequently in the past, although many of her admissions have been to her local hospital. Elena's outline of a typical day in hospital (see figure 5.4) highlights the disparity between her routine at home and that of being in hospital.



TYPICAL DAYS IN HOSPITAL (boo!)

in hospital / at home

TIMES	WHAT HAPPENS	WHO IS PRESENT	WHO IS INVOLVED
6am		wakeup! IVs	asleep!!!
7am	☹	awake + dress	asleep (still!) mum goes for bacon + eggs
8am		meds breakfast	physio + (if school) meds + IVs (sometimes)
9am		physio	School or
10am		IV's	having fun usually
11am	☹	school (boo)	
12pm		dinner + meds	lunchtime for me ☹
1pm		school	
2pm		IV's	
3pm	☹	bored	
4pm			home now, text friends who r u?
5pm		tea	internet ☺
6pm		IV's	tea (mum's cooking nicer)
7pm		physio (if early)	watch soaps ... Love Telly! ☺
8pm	☹	be bored	meds + physio
9pm			supper + computer → email friends
10pm		awake - can't sleep - hot	games + cousins ☺ asleep
2am		IV's	"

☺ Best time none

☹ Worst time everything really ... home is best

Figure 5.4 Activity by Elena

Saira

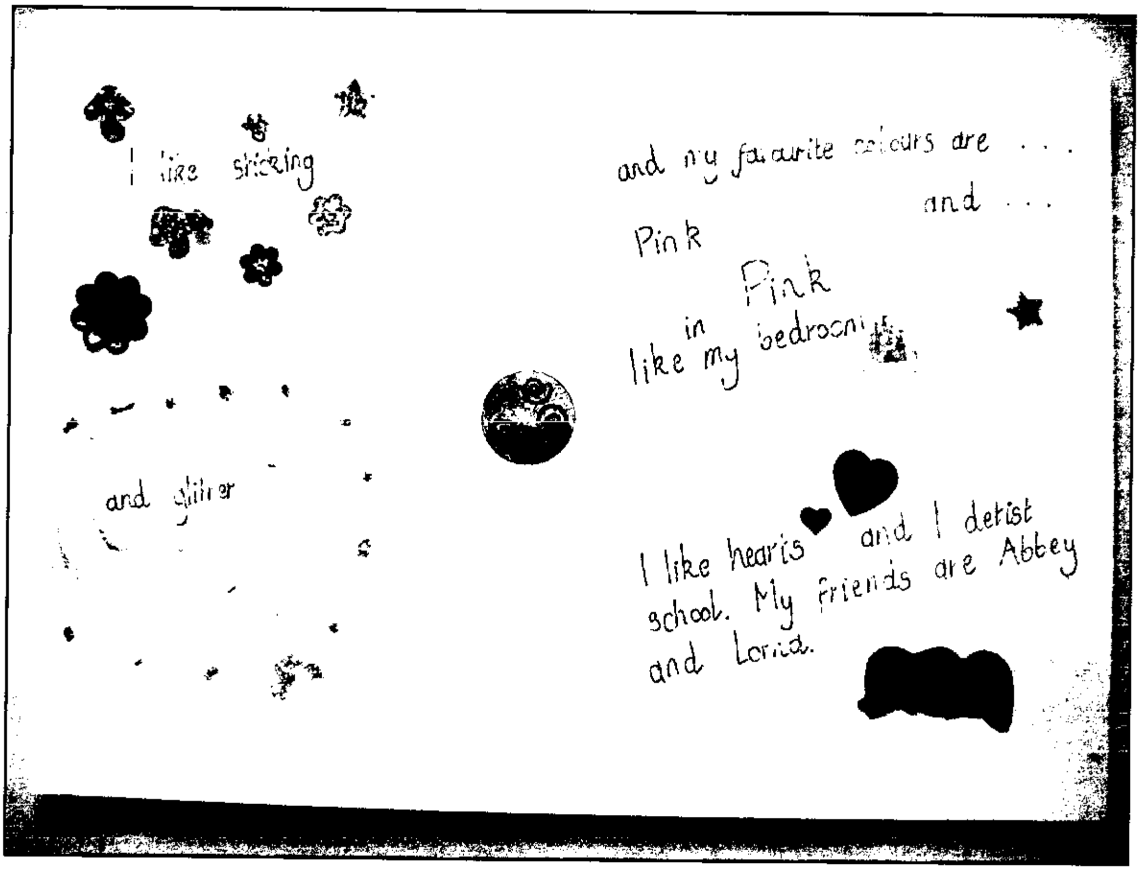
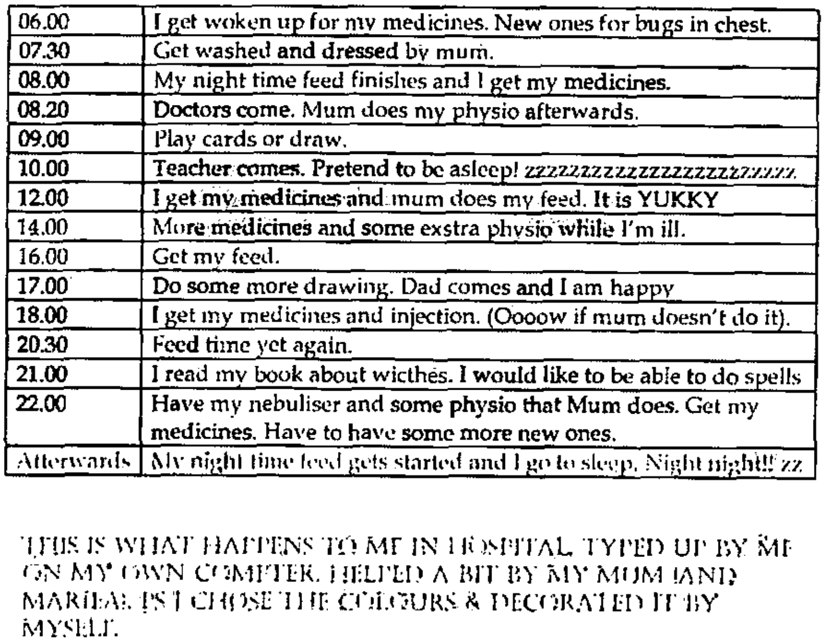


Figure 5.5 Drawing by Saira

Saira, (40) aged 9 years, was admitted as an emergency due to having a severe chest infection after being seen by her GP. Saira has cerebral palsy, resulting in her having a mild degree of learning difficulties and more extensive physical disabilities leaving her with complex care needs. Saira was an acute on chronic admission. She has had frequent admissions to hospital previously. Saira's description of being in hospital (see figure 5.6) depicts the way in which her routine is established around both her treatment needs due to her chest infection and also those arising from her complex needs.



06.00	I get woken up for my medicines. New ones for bugs in chest.
07.30	Get washed and dressed by mum.
08.00	My night time feed finishes and I get my medicines.
08.20	Doctors come. Mum does my physio afterwards.
09.00	Play cards or draw.
10.00	Teacher comes. Pretend to be asleep! zzzzzzzzzzzzzzzzzzzzzzzzz
12.00	I get my medicines and mum does my feed. It is YUKKY
14.00	More medicines and some exstra physio while I'm ill.
16.00	Get my feed.
17.00	Do some more drawing. Dad comes and I am happy
18.00	I get my medicines and injection. (Oooow if mum doesn't do it).
20.30	Feed time yet again.
21.00	I read my book about wicthes. I would like to be able to do spells
22.00	Have my nebuliser and some physio that Mum does. Get my medicines. Have to have some more new ones.
Afterwards	My night time feed gets started and I go to sleep. Night night!! zz

THIS IS WHAT HAPPENS TO ME IN HOSPITAL TYPED UP BY ME ON MY OWN COMPTER. HELPED A BIT BY MY MUM (AND MARIE). PS I CHOSE THE COLOURS & DECORATED IT BY MYSELF.

Figure 5.6 Illustration by Saira

Dominic

Dominic, (10) aged 13 years, was transferred to the ward from Intensive Care after being involved in a road accident. This was his first admission to hospital. His account describes his experience of being in Intensive Care:

> "First thing I remember was being in Intensive Care. ... All the machines and beeping and drips and wires. It's like being in a spaceship. And I felt sick and my head was killing me with all the ringing and bleeping".

Abby

Abby, (1) aged 9 years, was admitted to the ward as a list admission as part of on-going treatment for cystic fibrosis. Abby has been increasingly unwell recently and over the past year has required overnight ventilation to aid her breathing. She reflects on other people's perceptions of this in her account:

> "People just sometimes concentrate on my vent and they ignore me. It's like the vent is all they see and I just think why don't you look properly and see me. I'm here as well, not just the stupid machine".

Summary

In this chapter I have outlined the context of the study setting, before moving on to describe the children and young people who participated within the study. In providing this description I show that the physical environment of the ward and both the resources and routines within it are a present and structured backdrop to the experiences of children and young people, contrasting these with the ways in which they are experienced by the children and young people themselves.

In Chapters 6 to 8 I will explore the three main organising themes that I generated from my analysis and interpretation of the data. These organising themes are grounded in the accounts of the children and young people and provided me with a clear way in which I could make sense of their experiences. In the following findings chapters I explore these organising themes which are:

- Being in hospital
- Being ill and undergoing treatment
- Children's and young people's experiences of care and caring in hospital

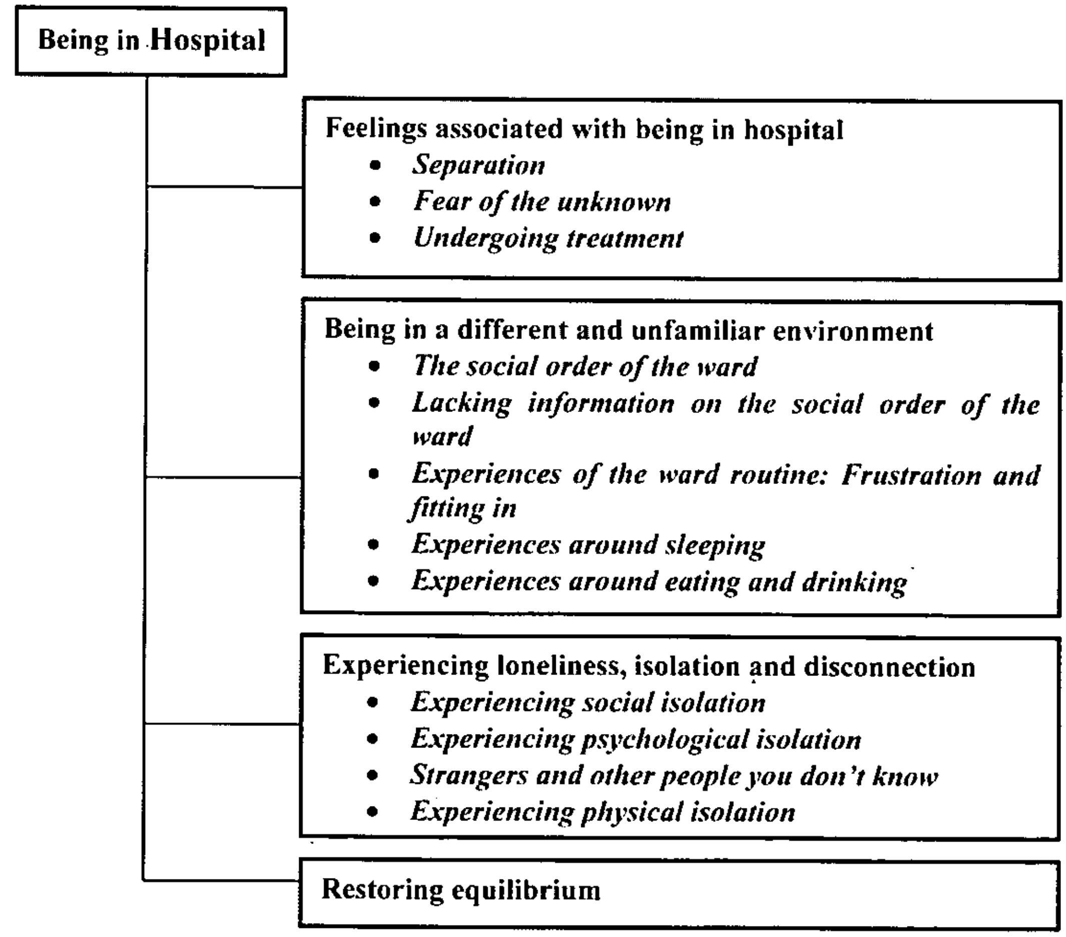
CHAPTER 6:
BEING IN HOSPITAL

CHAPTER 6: BEING IN HOSPITAL

> "There were lots of things that I missed at first because I wasn't at home. Like I've not got my toys and games with me and that does feel a bit funny even though there are games here that you can play with. You don't sleep in your own bedroom either. I've only ever slept in my own room except when I've been on holiday. I've never been in a big bedroom like this with other people. It feels a bit funny. I don't really like it" (Anna, (2) aged 7 years).

Introduction

Children and young people spoke in depth of their experiences of being in the hospital setting. These accounts highlighted experiences both specific to some individuals, and others integral to all children and young people, regardless of age or illness. This chapter is comprised of four themes, some of which have sub-themes, as represented in figure 6.1. Restoring equilibrium is presented as a recurring theme within each of the findings chapters.



Being in Hospital

Feelings associated with being in hospital
- *Separation*
- *Fear of the unknown*
- *Undergoing treatment*

Being in a different and unfamiliar environment
- *The social order of the ward*
- *Lacking information on the social order of the ward*
- *Experiences of the ward routine: Frustration and fitting in*
- *Experiences around sleeping*
- *Experiences around eating and drinking*

Experiencing loneliness, isolation and disconnection
- *Experiencing social isolation*
- *Experiencing psychological isolation*
- *Strangers and other people you don't know*
- *Experiencing physical isolation*

Restoring equilibrium

Figure 6.1 Outline of Chapter 6

Theme1: Feelings associated with being in hospital

Introduction

The children and young people in this study used a wide range of descriptors to describe their feelings about being in hospital including "unhappy, bored, lonely, don't enjoy it, sad, makes me bad tempered, have to put up with it." One of the most common words used was sad. This was demonstrated in an activity sheet completed by Sarah (42), portraying her feelings about being in hospital which described "I feel sad when I am sick in hospital" (Sarah, aged 11 years). Sadness was frequently described regardless of age and experience when children and young people expressed their experiences of being in hospital. Sadness was linked to other emotions as Malachi (31) explained:

> "I hate having to come into hospital. It's just the worst feeling. It just makes you feel down having to come in, like sad. I just want to be at home" (Malachi, aged 13 years).

Sadness was depicted also within a drawing (see figure 6.2) produced by Poppy, (39) aged 6 years. Poppy drew this picture of a sad face with tears when invited to draw a picture to depict her feelings about being in hospital. Conversations with Poppy about the drawing afterwards led to her explaining "the poor little girl is in hospital and she is crying because she misses her mum and cat".

Figure 6.2 Drawing by Poppy

The wide range and depth of feelings experienced by the children can be identified in the following activity sheet (see figure 6.3) completed by Emily, (13) aged 12 years, who had extensive experience of hospitalisation due to having a long term condition. Emily completed the activity and not only talked about the feelings being in hospital incurred but described the factors that contributed to these:

> Maria: "So, can you tell me about this one. .... this balloon that says feeling sad."
> Emily: "Well, I feel sad when I have to have medicines because they taste horrible. Injections as well. I'm scared of those. Look I've put injections, well needles in the frightened balloon. Well, other things make me sad as well being here. .... Like missing my pets and my family and friends".
> Maria: "Do they?"
> Emily: "Hmm. I feel sad and upset because I miss them so much and I have to be in hospital. And sad then because I hate having to be here and having yukky medicine" (Emily, aged 12 years).

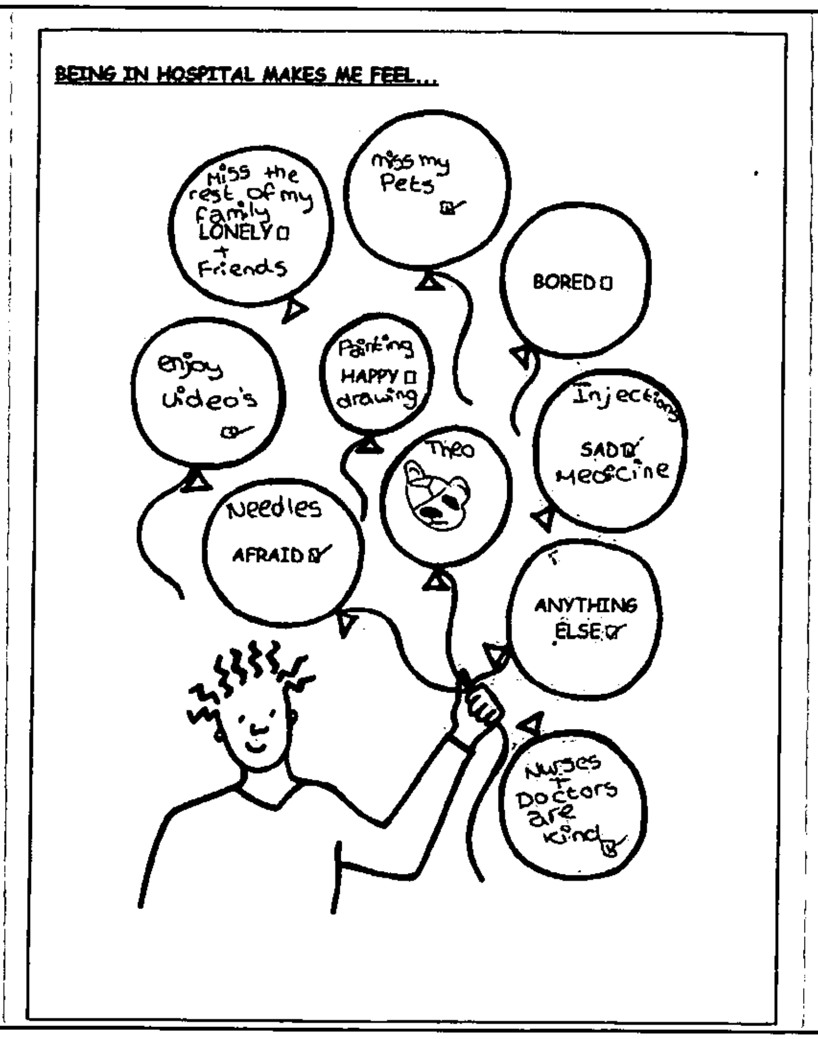


Figure 6.3 Activity by Emily

For the majority of children and young people fear was a central factor, regardless of previous hospital experience. Indeed, whilst all of the children and young people were aware of their need to be in hospital in order to receive treatment for an illness or condition, this did not appear to reduce their anxieties about the hospitalisation. Instead they expressed a range of fears in relation to being separated from parents and other people important to them, fear of the unknown, specific anxieties around undergoing treatment and fears regarding being in an unfamiliar environment. I will describe these next.

Separation

Anxiety around being separated from those people important to children and young people was integral to their experience of being in hospital. Predominantly children and young people spoke about missing parents and family, but friends and pets featured also within their accounts. Discussions around those missed often formed a large part of their stories. For example, James (21) commented that:

> "I've missed everything while I've been in here. I've missed my mum and my friends. Most of all I've missed my hamster, Harry. I've even missed my sister a bit and I can't stand her" (James, aged 12 years).

Fear of being separated from those important to them was felt particularly strongly by the younger children. Benito, (5) aged 6 years, commented that "I'm so glad that my mum's here. I would have wanted to go home if my mum wasn't staying with me". Older children and young people however, also experienced anxiety around separation. Hannah, (17) aged 15 years, spoke of "missing all my family. They can't get in to see me everyday because it's too far. I miss them loads".

Separation from those who were important to children and young people resulted not only in fear, but also in feelings of loneliness and vulnerability. Loneliness will be discussed separately later within this chapter in the theme entitled "Experiences of loneliness, isolation and disconnection".

In the next sub theme I describe the ways in which children and young people were fearful of "the unknown".

Fear of the unknown

Feeling afraid of the unknown was central to the accounts of children who had limited experience of hospitals. For example, on being asked about what made her feel afraid, Violet, (44) aged 9 years, commented "when I don't know what's going to happen to me". Other fears included anxieties about the staff and how they would respond to them, concerns about events associated with treatment and investigations, fears around getting well again and anxiety around being separated from family. This is depicted in a list of "Things I thought about when I came into hospital" drawn up by Olivia, (36) aged 7 years, during her first admission to hospital:

> "What will they do to me?
> What will happen to me?
> Will I ever get better?
> Will the doctors and nurses be kind to me or not?
> Will my mum be able to stay all the time?
> What will the food be like?
> Will my rabbit, Jemima, miss me?
> (PS I don't know as this is my first time in hospital)".

This list, representing a comprehensive set of questions, suggests that Olivia had given her admission a great deal of thought. Indeed, conversation with Olivia during the compilation of her list demonstrated that she had attempted to prepare herself for coming into hospital by thinking through what being in hospital might be like. However, other children admitted to hospital as an emergency had little opportunity to prepare for the experience. For example, Joshua, (23) aged 12 years, commented that:

> "One minute I was at the doctor's and then the next minute I was here. No wonder I don't know whether I'm coming or going or what's happening to me".

Whilst fear of the unknown was associated predominantly amongst those children and young people who had limited or no prior experience of hospital, it is salient to note that children with extensive experience of the ward setting often entered a situation where important elements of the setting were unknown to them. For instance, Samuel (41), who had numerous previous admissions to the ward, noted that many of the nursing staff were unknown to him at the time of his participation in the study:

> "... mainly the nurses end up leaving. It's a shame for us 'cause we just get to know them well and then they go and leave. It's good though that they get new jobs that they want and move on. ... It's just a shame that we end up hardly knowing anyone" (Samuel, aged 16 years).

For Samuel, being in a situation whereby many of the ward nurses were unknown to him despite numerous past admissions to the ward was a source of upset and one that he referred to frequently during his account. Samuel spoke repeatedly of a ward he used to be an inpatient on where staff and children were well known to each other, using this to provide a stark comparison to his present situation. It would appear that instances where children and young people were unable to build relationships with the ward staff impacted negatively upon their experiences, adding to their feelings of fear and loneliness. This indicates that certain elements of the hospital setting can remain unknown and anxiety provoking to children, regardless of extensive past exposure to the environment. I next describe children's and young people's specific feelings around undergoing treatment.

Undergoing treatment

The majority of children highlighted anticipatory anxiety regarding the treatment they would have to endure whilst being in hospital. Regardless of age, fears were voiced concerning having to take medications, having to undergo treatments and surgery, being in pain and in particular, having to receive injections:

> "I feel frightened when having blood tests and operations. Anything to do with needles really" (Emily, (13) aged 12 years).

Other children highlighted concern around observing other children undergoing treatment. For one child, specific fears were associated with witnessing emergency situations on the ward. For instance, Lydia (29) described feeling frightened:

> "when you see all the nurses rushing about because something's happened. It's just like on Casualty (TV programme) when they all run about" (Lydia, aged 10 years).

Children's and young people's anxieties in relation to undergoing treatment were an integral aspect of their fears in relation to being in hospital and fear of the unknown and are therefore discussed in this theme. [Note: In Chapter 7 children's and young people's specific experiences of undergoing treatment will be discussed]. In the next theme I set children's fears in context by describing their experiences of the ward and its organisational routines and practices.

Theme 2: Being in a different and unfamiliar environment

Introduction

Children's and young people's anxiety appeared to be elevated by being in an unfamiliar environment and was further compounded by feelings of uncertainty about being in hospital. This appeared to create feelings of insecurity and fear, even in children and young people who had experienced previous hospitalisations. Indeed, all the children and young people described the strange and different nature of being in hospital, not only in relation to the physical environment itself, but also with regard to the social order of the ward; that is the organisational routines and practices of the setting. For the purposes of this thesis, environment refers to the contextual setting of the hospital and ward and includes both the physical setting and the organisational structures which impacted upon children's experiences. This theme explores the very different nature of the ward setting from the perspectives of children and young people and includes their perspectives of the social order of the ward, in particular the ward routine.

The children and young people who participated in the research had a varied experience of both hospital and the study ward itself. For some children, this hospitalisation was their first ever admission to hospital, whilst others had extensive experience of being both in hospital and the study ward itself. For the former group of children and young people the "strangeness" of being in hospital was particularly vivid. Anna (2), aged 7 years, commented that she thought "that being in hospital is dead funny. Not scary but strange". This account compared favourably with Minna's (34) story describing her admission to hospital:

> "On Thursday I came into hospital. Being in hospital is well, what shall I say, it's like nowhere else you've ever been before. Different to school and Brownies and very different to going to my nan's. I had to go to hospital as I was poorly and needed to get better. But now I'm better and I'm going home and I'm happy that I don't have to be in hospital any more. The end" (Minna, aged 5 years).

For other children and young people, recurring admissions meant that they were "regulars" who knew both the hospital and ward environment and its routines well. However, interestingly this group nonetheless articulated the different nature of being in hospital, suggesting that despite having experienced the setting previously, this continued to affect their experiences. Isaac (19) described being in hospital in the following way:

> "It's not like being at home. It's very different ... to being at home. In some ways you get used to it but in other ways you never do because you just want to be back home and back to what feels right" (Isaac, aged 13 years).

The notion of hospital "being different" was referred to frequently by children and young people, regardless of previous experience of hospitalisation. It appeared that this compounded children's and young people's experiences negatively whereby they struggled to settle into a setting unlike any they had encountered before. Children and young people described finding the hospital setting unlike other settings and places familiar to them:

> "All the times are wrong here. Like we don't have tea at the same time as we do at home. I'm used to having tea at home with just my brother and me and it's different here. It seems a bit funny to eat your tea in bed with lots of other people that you've never even met. Everything just seems back to front here. It's all done at the wrong time" (Anna, (2) aged 7 years).

Conversations with both children and young people revealed that they compared the hospital environment and its practices with other settings with which they were familiar with. These included school, religious settings, out of school clubs, respite centres and for one young person with a long standing illness, a children's hospice.

Children's accounts revealed the impact the very different nature of hospital added to existing feelings of uncertainty and fear:

> "The worst thing about hospital is that it is dead different to being at home, to being anywhere else really. It makes you miss home and your friends and your family even more" (Katie, (24) aged 7 years).

Children and young people new to the hospital setting appeared to base their preconceptions of hospital on a variety of sources including television programmes, information from friends and experiences of visiting relatives in hospital. This latter source was most often related to adult hospitals and as such highlighted the differences between settings for children and adults:

> "It's not like my grandad's hospital this one. When I went to see my grandad it was different and you had to be quiet. At least this hospital's got toys and things you can do" (Daisy, (9) aged 6 years).

On occasion experiencing hospital as a patient firsthand resulted in children's anxieties being lessened. For James, (21) aged 12 years, hospital was described as being "OK. I was scared at first as I've never been in hospital before, but it's a lot better than I thought it would be". This draws attention to the, often false, misconceptions regarding hospital that can heighten children's anxiety.

It would appear that children and young people remained fearful of being in hospital, even after having undergone multiple previous admissions. Often this was due to fears around hospitalisation continuing to exist regardless of past experience. These included anxieties around separation from parents, family, friends and normal daily activities; coming into contact with hospital staff and fears related to treatment. In some instances where past exposure to the ward setting had resulted in a negative experience, these fears were often intensified:

> "Last time I was in hospital it was just so awful. I ended up being in for a month and was really ill. It was really traumatic ... When they said I had to come in again ... I've just been dreading it" (Isaac, (19) aged 13 years).

In the next sub theme I describe the social order of the ward in which the study was set.

The social order of the ward

Children and young people admitted as patients to the ward were subject to the routines and practices in place; the social order of the ward. The ward routine has previously been described in Chapter 5 but there were other aspects related to the social order. There appeared to be many rules regarding what was deemed as appropriate behaviour, alongside certain demands associated with the role of being a patient within the ward. This resulted in children and young people needing to familiarise themselves with the rules and routines of the ward alongside the expectations of the ward staff. This was no mean feat as the accounts of children and young people highlighted their uncertainty regarding the routines and practices in place and their associated rules and resultant expected behaviour.

In part this uncertainty resulted from the ways in which the rules were instigated. Whilst some of the ward rules were stated explicitly by written notices and verbally by the ward staff, others were implicit and learned only after spending time within the ward setting. Examples of some of the explicit and implicit rules of the ward are given in tables 6.1 and 6.2. Where the rules were not clearly explicated by the ward staff, this added to children's and young people's uncertainty as to what was expected of them as Oscar (37) explained in a slightly exasperated way.

> "It's like you don't know what you can do and what you can't do. You get told off because you get some things out of the cupboard in the playroom and then when you're sitting there with nothing to do somebody else says well why don't you go and help yourself to something to do. If they could tell us it would at least be a start" (Oscar, (37) aged 11 years).

Table 6.1 Examples of explicit ward rules

Parents	Only one parent allowed to stay overnight. Parents allowed to sleep in fold up bed by child's bed but not in chairs or elsewhere in ward.
Kitchen and food rules	Children and parents not allowed into ward kitchen. Children and parents not allowed to serve food from ward trolley. Parents not allowed to bring food and hot drinks out of parents' room. Children not allowed in parents' room.

Table 6.2 Examples of implicit ward rules

Children	Not to watch television or play computer games early in the morning.
Visitors	No more than two visitors allowed to visit at any one time. Visitors not allowed after eight pm.
Sleeping time	Lights to be turned down early in bays where young children present. Children not allowed to watch television or play computer games late at night. Children not allowed to sleep late in morning.

The accounts of children and young people indicated that perhaps contrary to popular belief, rules were both preferred and accepted. For example, Anya (3) commented that:

> "You have to have some rules otherwise everything would fall to pieces. Like everywhere has to have rules, you know, like at school and when you go to work" (Anya, aged 15 years).

It would appear that the imposition of rules provided children and young people with boundaries and a clear viewpoint of others' expectations of them. However, to further add to children's and young people's feelings of uncertainty it appeared that the rules were often arbitrarily applied depending upon the members of ward staff on duty:

> "When [staff nurse] is on at night I'm allowed to come out of the cubicle and sit at the nurses' desk and go on the internet. But if any of the others are on I get in trouble if I even leave my room" (Isabelle, (20) aged 14 years).

It appeared that in some instances children and young people found the rules nonsensical:

> "My mum and dad aren't allowed to eat their tea with me because it's against the rules. They have to go downstairs to eat it and I have to sit in bed by myself. Don't you think that's stupid?" (Anna, (2) aged 7 years).

Whilst Anna and her family complied with the rules around parental eating on the ward, for other young people instances where rules appeared to be meaningless to them deliberately ignored them:

> "I told them (nursing staff) that I was going to sit in the parents' room and have a drink with my mum. She was saying that I couldn't but my mum had come to see me and she wanted a drink and she's not allowed to have one on the ward. Oh yeah, it makes a lot of sense for my mum to drive for an hour to see me and then for her to sit in the parents room with a cup of tea and me to sit on my own in bed" (Anya, (3) aged 15 years).

In the next sub theme I outline the ways in which children and young people lacked information on the social order of the ward.

Lacking information on the social order of the ward

Children's and young people's uncertainty regarding the ward setting appeared to be hampered by a lack of information on the rules, practices, routines and layout of the ward. Frequently children reported lacking information on the general layout of the ward environment, including where toilet, bathing and play facilities were located. Other children's and young people's accounts indicated that they required information on areas and facilities they were allowed to access, including staff offices and supplies cupboards. Often it appeared that this was a result of a failure to orientate children and young people to the ward when it was new to them. For example, Abby (1) commented that; "in my own hospital (local hospital usually attended) I know where I can and can't go but here I don't" (Abby, aged 9 years). Other children and young people commented on lacking knowledge about the ward routines and timing of events. It appeared that this lack of information regarding the ward social order contributed substantially to the uncertainty of children and young people.

In order to gain the necessary information children and young people reported observing others or directly asking fellow patients and parents about facilities and practices on the ward:

> "My friend over there showed me where the playroom is and where the computer is otherwise I wouldn't have known" (Mia, (32) aged 7 years).

Significantly children and young people tended to rely on sources other than the nursing staff for gaining information about the ward. This appears starkly in the account of a child during her first admission to hospital:

> "I don't like to ask the nurses as they're always busy and don't have time to tell us" (Olivia, (36) aged 7 years).

Meanwhile, for other children the ward rules were learnt only when these were broken leading to chastisement by members of staff:

> "I didn't realise you couldn't go into that room down there until that doctor came and told me off" (Elijah, (12) aged 8 years).

In this sub theme I have described the ways in which children and young people lacked information on the social order of the ward. In the next sub theme I describe their experiences of the ward routine.

Experiences of the ward routine: Frustration and fitting in

As described in Chapter 5, daily events in the ward were structured around a set routine. These included set times for events associated with treatment, such as the administration of medications, physiotherapy, ward rounds and procedures and those based around the basic needs of the children, such as eating, sleeping, getting up and meeting hygiene needs. The ward routine dominated the structure of the children's and young people's days and thus featured heavily in their accounts. Regardless of age, children and young people highlighted the unchanging structure of the ward days. For example, when discussing daily life in the ward Milly (33) commented that:

> "Every day's the same. It's like this happens at this time and this happens at that time. Nothing is ever different or changes" (Milly, aged 9 years).

Although some children and young people might find that a highly structured setting would offer security and provide reassurance, particularly in an unfamiliar environment, others consistently highlighted the inflexibility of the ward routine and the ways in which this impacted upon their experiences. Field notes recorded during the initial period of observation noted the ways in which the ward routine impinged upon the experiences of children and young people:

> [The children and young people seem to be given very little control over the ward routine. It seems very inflexible. For instance, it's very difficult for children to access food and drinks at times other than the set meal times. This seems particularly obvious when the nurses are busy and unable to make snacks or bring drinks. Today this impacted upon the care of one child who missed a meal due to feeling unwell at lunchtime but wanted a snack later on] (Fieldnote).

It was evident during the period of preliminary observation that children and young people were expected to conform to the ward routine. Indeed where children and young people failed to comply they were at the risk of censure from the ward staff as Leila (25) commented:

> "Well I got done (chastised) by one of the nurses because I went into the parents' room. I went in there to sit with my mum while she had a drink, and it was teatime and I couldn't eat because I wasn't allowed, but she said that I had to be on my bed while it was teatime whether I was eating anything or not" (Leila, aged 10 years).

As the above excerpt shows, ward staff had a clear expectation for children and young people to adhere to the ward routines and practices, even in instances where the practice may not be relevant to individual children and in fact seemed meaningless. Next I will describe the ways in which the ward routine impacted upon children's and young people's specific experiences.

Experiences around sleeping

It seemed that children and young people were expected to comply with the daily routines and practices of the ward. These expectations extended to all elements of the children's and young people's basic needs including those around sleep. Within the ward, certain rules were in place regarding set times for settling down to sleep and waking up. This was supported in children's and young people's accounts as they reported instances when they had to wake up at a particular time and Lydia's (29) description reflects the strangeness of this:

> "They come and tell me to get up. They should leave children to sleep whenever they can 'cause sleep is sleep and it's good for them. This morning they woke me up at half past eight and I had a headache the night before that and I weren't very well 'cause I had like tummy ache and I had a headache and I told her that I didn't feel very well" (Lydia, aged 10 years).

Meanwhile other children spoke of having to settle into bed at a time they felt was too early for them. The drawing (see figure 6.4) by Violet, (44) aged 9 years, depicted her feelings around having to go to bed at night time whilst in hospital. She explained her picture by stating that the nurses told the children to go to bed and it made her feel sad and alone lying in bed when she was unable to sleep. The smaller drawings on the right hand side of the drawing were of things she would rather do before settling into bed at a later time. This would suggest that the ward routines were compounding underlying feelings of sadness and loneliness.

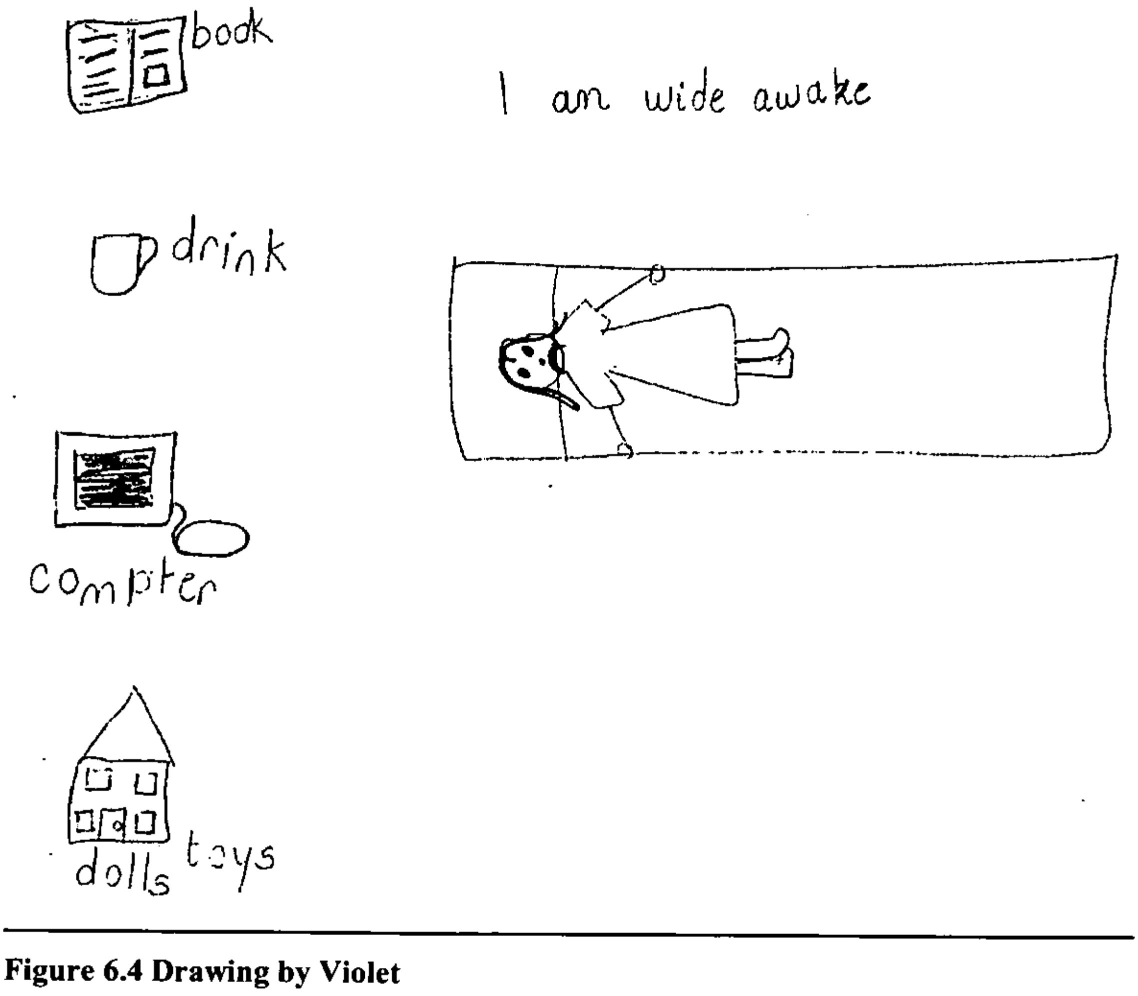


Figure 6.4 Drawing by Violet

The lack of control that children and young people experienced over sleeping and waking was of concern to them. This was particularly heightened whilst they were in a new environment often resulting in problems sleeping and suffering from illnesses potentially leaving them requiring more rest. Many of the children and young people spoke about being unable to sleep and then being woken during the night or early in the morning. Indeed, waking up early due to the ward routine featured often in children's and young people's accounts and Libby's (26) account is typical:

> "They wake you up first thing in the morning taking your temperature. I wouldn't mind but they woke me up as well in the middle of the night as well sticking that thermometer in me" (Libby, aged 12 years).

For other children and young people who felt unwell and had suffered from disturbed sleep at night time this resulted in them attempting to sleep during the day. However, often this was futile as they were often disturbed, as is evident in the next two excerpts:

> "I've been waking up 'cause people have been in and out constantly but if I were left on my own then I wouldn't be up now. I'd still be fast on" (Isabelle, (20) aged 14 years).

and

> "I tried to get some sleep yesterday morning because I felt that tired and ill but then the teacher came and woke me up and said I had to do some sums" (Leila, (25) aged 10 years).

Not only did the routine of the ward impact negatively upon children's sleep experiences in terms of imposing set times but also on those occasions where it failed to take into account children's individual preferences and requirements. For example, Anna (2) commented:

> "At home I go to bed at half past eight after Eastenders on the nights it's on. Here we have to go to bed at about seven o'clock. I always read my book at home before I go to sleep but I can't here because they turn the light off and it's too dark to read. We don't get a drink at bedtime either and I can't sleep if I don't have one" (Anna, aged 7 years).

Instances where the individual preferences and requirements of children were ignored impacted negatively upon children's experiences. This lack of acknowledgement of their wishes is also pertinent to the following presentation of children's and young people's experiences around eating and drinking and treatment which I will describe next.

Experiences around eating and drinking

Many rules were in existence around the provision of food and drinks to children and young people within the ward setting. As demonstrated in the explicit and implicit ward rules, children and young people were limited in their access to food and drinks as they were prohibited from entering the kitchen or obtaining food directly from the trolley. This necessitated in children and young people having to rely on the nursing staff or other adults to provide food and drinks. As already explained, at times when the nurses were extremely busy children and young people often had to wait for long periods of time before someone was able to fetch provisions for them as Katie (24) explained:

> "I wanted some orange but I've had to wait for ages before someone could get it for me. I think they should have it where we can get it for ourselves" (Katie, aged 7 years).

Other children meanwhile felt uncomfortable asking for food when the nurses were busy as requests might be met with disapproval. For Joseph (22), being chastised at asking for a drink had left him anxious and he had decided not to risk the censure of the staff again:

> "She was really off with me when I asked her for a drink. ... She said she only had one pair of hands but it's not my fault that she's busy. I didn't mean for her to get it that second. I don't want to be a nuisance and I know they're busy, but I can't get out of bed when I'm tied up to these" (pointing to oxygen and monitor) (Joseph, aged 10 years).

It is pertinent to note that where children and young people were unable to obtain food and drinks this was often contrary to their treatment where, for example, taking a certain amount of oral fluids or food was deemed important. One case which illustrates this point was highlighted by Lydia (29), who due to having cystic fibrosis required a high calorific diet. As a result of this, good practice to treat her condition deemed it essential for Lydia to eat snacks regularly throughout the day. However, Lydia reported that this requirement had not been met:

> "But I'm allowed snacks during the day because it's important for me to have lots of calories and I've been here for nine days and the nurses haven't been bothered to go down to the canteen and get me anything" (Lydia, aged 10 years).

For others, failure to take into account individual food quantities and preferences resulted in either a poor dietary intake or young people having to make alternative arrangements at mealtimes:

> "I have to go down there (to the canteen) 'cause toast and beans isn't enough for somebody's tea. Well, it isn't enough for my tea anyway. I suppose it would be like for three, four year olds. They don't eat a lot do they?" (Samuel, (41) aged 16 years).

In the next sub theme I continue by outlining children's and young people's experiences around the timing of both treatment and procedures.

Experiences around procedure and treatment times

The timing of procedures and treatments were dominated by the routine and practices of the ward. For many children and young people the timing of events around these were highly significant. Children and young people with past experience of being in hospital, and indeed those who had been on the ward for only a few days, appeared to be aware of the timing of procedures related to treatment such as medications and dressing changes. Subsequently, all the children and young people deemed it important to adhere to these procedures administered by the hospital professionals. As a result, many became anxious when these procedures deviated from the expected times. Predominantly the late administration of medications figured in accounts:

> Isabelle: "Tell you what's really hard work. Say the same treatments due at twelve o'clock or treatments due at four o'clock, it's always half an hour or an hour later".
> Maria: "Is it? Do you mean the medicines?"
> Isabelle: "Yes. Well I went looking for them yesterday. And my mum went looking for them t'other day".
> Maria: "The nurses? Was that to get your medicines?"
> Isabelle: "My IV's. But when I get home I can make it into me own routine. Or my mum can."
> Maria: "Yes."
> Isabelle's mum: "Say it's going to be eleven o'clock, I can get it done for eleven. They've got too many patients to be seen to be given specific times" (Isabelle, (20) aged 14 years).

Indeed, children and young people often spoke of having to remind nurses that their medications were due:

> Maria: "And is it nicer for you that your mum is here to do your IV's?"
> Hannah: "Yes, 'cause I can get 'em or she'll go chase 'em."
> Maria: "Do you mean chase the nurses?"
> Hannah: "Yes. They don't like chasing but we wouldn't get the IV's otherwise" (Hannah, (17) aged 15 years).

Isabelle's account highlighted her viewpoint that within the home setting her treatment could be administered without impediment and thus more effectively. It appeared that many children and young people were concerned that a delay in the administration of their medications or treatments could impede their recovery. For other children and young people the late administration of some medications could result in them suffering from unpleasant symptoms such as pain. As presented earlier, being in pain was a central fear. However, many children and young people described instances where they had to wait for pain relief, for example:

> "Yesterday night I wanted something and it took them about half an hour to get me something. And by the time they got me something my stomach ache had gone away. I said it doesn't matter now" (Lydia, (29) aged 10 years).

Meanwhile, for other children and young people with complex treatment protocols, delays in one aspect of their treatment could severely hamper the execution of the rest of their required therapies.

> "When you're here you sort of have to fit into their time ... The routine is the same as it is at home, you know, physio [physiotherapy], IV's, but here 'cause you can't keep your own medicines with you, you end up with everything going to pot because no one brings what you need on time. So you have to ask for your neb [nebuliser] and it's late and then that means you're not ready when the physio comes. So after you've had your physio late you're already late for your IV's but nobody brings them to you. So you wait for a bit because you know everyone's busy and you don't want to look as if you're hassling them. In the end you have to ask and you've still not had your breakfast, never mind a snack in the middle of the morning. It just gets you mad because you're in hospital 'cause you've got a bad chest and I'd get things done better at home" (Callum, (6) aged 15 years).

It would appear that children and young people were drawing attention to the discrepancies between their own individual routines and those instigated by the ward. Indeed as the above accounts show, the usual treatment routines initiated by children and young people with chronic illnesses contrasted strongly with those provided within the hospital setting. The failure of the ward to provide care and treatment alongside the usual routines of the children and young people clearly impacted negatively upon their experiences as Louise commented:

> "You have your own routine at home that you're used to and then when you come here it all goes to pot. It's just a pain to have your routine turned upside down. I know that the nurses are busy and you can't expect that everyone does everything round just what you want, but I think it's bad when your medicines and that are late all the time. It's like you're not trusted to keep your own medicines but yet they're doing a much worse job than I could do myself or me and my mum do at home. You do feel as if you have to fit around everyone else and the way the ward works. Last time I was in there were three of us all on IV's and all of us were getting them late all the time and I just think ... well if three of us are late with our stuff all the time who are the nurses, or I don't know, the ward working round" (Louise, (27) aged 16 years).

This is of particular significance as care based around the individual needs of children and young people is frequently extolled by children's nurses as a central tenet of children's nursing.

It appeared that children and young people experienced the ward setting as being both different and unfamiliar. This, alongside uncertainties regarding the social order of the ward heightened existing fears and anxieties. The routine of the ward was experienced as being inflexible, lacking a good fit with the requirements of individual children and young people. As such children and young people expressed concerns that they had to "fit into" the ward routine which became a source of frustration to them. Alongside these experiences, children's and young people's fears remained. In the next theme I describe children's and young people's overwhelming feelings of loneliness and isolation in order to further provide a greater context to their fears.

Theme 3: Experiencing loneliness, isolation and disconnection

Introduction

The children and young people in this study described suffering from intense feelings of loneliness and isolation during their stay in hospital. Often these feelings of isolation impacted upon many aspects of children's and young people's experiences of being in hospital, resulting in feelings of being disconnected. In this theme I explore the loneliness and isolation experienced by children and young people from three perspectives; social isolation, psychological isolation and physical isolation.

Experiencing social isolation

It appeared that children and young people frequently experienced social isolation whilst they were in hospital due to an interruption in their normal everyday routines and activities. These included a breakdown in usual routines around going to school or pre-school groups, out of school clubs, activities and hobbies. Irrespective of age or experience of being in hospital, children and young people referred to yearning for their normal everyday routines and activities. For instance, Stephen (43) commented that "I really wish that they had a play area where you could go outside and play football. That's what I miss most. I play football every day at home" (Stephen, aged 12 years).

For other children and young people hospitalisation resulted in missing out on planned events that were important to them including holidays and sporting events. Meanwhile others expressed anxieties about missing school and falling behind with schoolwork:

> "I should be doing my mock GCSE's at school next week and I'm missing out on all the revision whilst I'm here" (Louise, (27) aged 16 years).

It would appear that the interruption to normal everyday routines and activities brought about by being in hospital led to feelings of social isolation and disruption in children and young people, resulting in feelings of loneliness and disconnection. However, children and young people often described suffering not only social but also psychological isolation and I will discuss this in the next sub-theme.

Experiencing psychological isolation

All children and young people drew attention to the separation from parents, siblings and other family members, friends and pets that hospitalisation incurred. Of these, children's and young people's accounts clearly identified the ultimate importance of their parents' presence to them whilst they were in hospital. This is depicted in a drawing (see figure 6.5) by Katie, (24) aged 6 years, who when invited to produce a drawing of herself in hospital produced a picture of herself and her mum in an outside setting. On asking Katie about her picture she explained that as her mum was with her it did not matter that she was in hospital as it still felt like being outside and being happy.

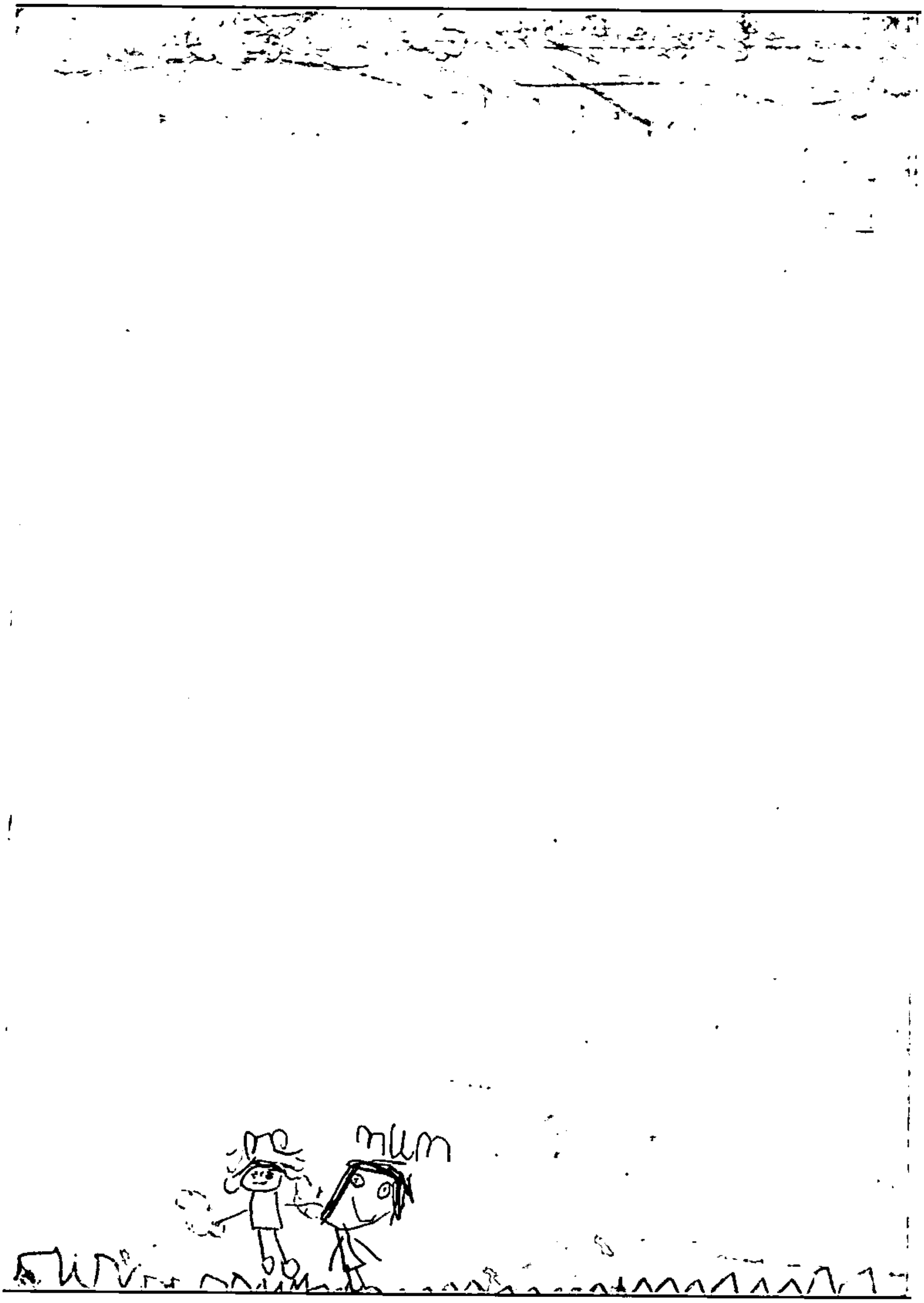


Figure 6.5 Drawing by Katie

For some children however, even where one parent was resident with them, feelings of being separated from the other parent were still significant as was identified in the following account:

> Maria: "Everyone's here today aren't they?" (referring to presence of child's mother and two grandmothers).
> Violet: "My dad's not".
> Maria: "Oh, but he's at work isn't he? Is he busy at work?"
> Violet: (Nods).
> Maria: "Yes? It's lovely you've got your mum and nan nans here, isn't it?"
> Violet: "Yes, but I would like my dad as well" (Violet, (44) aged 9 years).

Whilst it is a reasonable expectation that younger children would miss their parents, the accounts of older children and young people indicated their distress at missing parents also. For Stephen, (43) aged 12 years, being in hospital when his mother was not with him was described as "the worst bit about being in hospital because I miss her so much".

Indeed, throughout the period of preliminary observation, all the children and young people, without exception, appeared to be more secure and less anxious when parents, family and friends were around. Thus it appeared that the presence of people, who children and young people viewed as being important to them, had a positive influence on their experience of being in hospital.

Children and young people described the important nature of their parents' presence in light of the unique relationship between them. Their accounts highlighted parents' awareness of their specific and individual needs and, in the context of the ward setting, parental presence ensured that these were met as much as was possible within this particular environment. Indeed, the accounts of some children and young people indicated that they believed these needs might not be met if their parents were not present. The children and young people viewed their parents as acting as their advocate as Isaac (19) clearly felt:

> "My mum knows just what to do for me like nobody else does. And if she's here she can look after me and make sure I get the things I need otherwise I might not get them" (Isaac, aged 13 years).

For some children and young people there was a clear moral expectation that their parents would be with them whilst they were in hospital:

> "My mum has to be here because I'm here. Well, she has to be because she's my mum. She couldn't not be with me" (Joshua, (23) aged 12 years).

Emotional reasons were given also by children and young people as to the essential nature of their parents' presence. For both young and older children the reassurance of having the presence of a parent was paramount. Children and young people across all age groups identified their vulnerabilities and anxieties regarding being in hospital and identified the ways in which their parents' presence helped with these. For example, Katie, (24) aged 6 years, commented that "I need my mum here because I'm quiet and the nurses might forget about me". Meanwhile, for other children being ill and in hospital for the first time were significant factors and Joseph (22) is typical in explaining why it was important for his mother to be with him:

> "Like it's my first time in hospital so I don't know what to do, you know, what to expect. I've been feeling too poorly to get out of bed as well so my mum can make sure I'm OK and that I've got what I need" (Joseph, aged 12 years).

It appeared that parental presence normalised the hospital environment for children and young people. Children and young people viewed the hospital setting as being uncertain and different in comparison with other settings they were familiar with. However, when parents were present with children these effects appeared to be lessened:

> "It's nice to have mum here. She runs about after me and does all the things she does at home. She makes it a "home from home" for me" (James, (21) aged 12 years).

James's account indicates that the presence of parents aided in coping with the unfamiliarity of the hospital setting even though he missed the normality of home and everyday routines. Children's and young people's comments suggested that they believed that their parents' presence was a means of protection and support from the adverse effects of being in hospital and this was achieved through their unique knowledge and insight aiding their coping and adjustment skills. The accounts of children and young people identified also the integral nature of parental presence during their treatment experiences. This is explored further in Chapter 7.

However, it is important to recognise that young people were aware of the limitations to their parents' presence. For Oliver (35) whilst it was important for him that his mother was resident with him in hospital he identified the limits imposed that even his parents' presence couldn't ease:

> "It's good that my mum's here but even so I'm still in the same bed and I still can't move about and there's still nothing to do" (Oliver, aged 13 years).

Children and young people described missing not just parents but also siblings, grandparents and other members of the extended family. The "People who are important to me" activity (see figure 6.6) was valuable in encouraging Milly, (33) aged 9 years, to discuss the people who are important to her and to think about those she missed whilst she was in hospital. For Milly, discussion around the activity identified particularly her feelings around missing her brother who was unable to visit her due to his intense fear of hospitals.

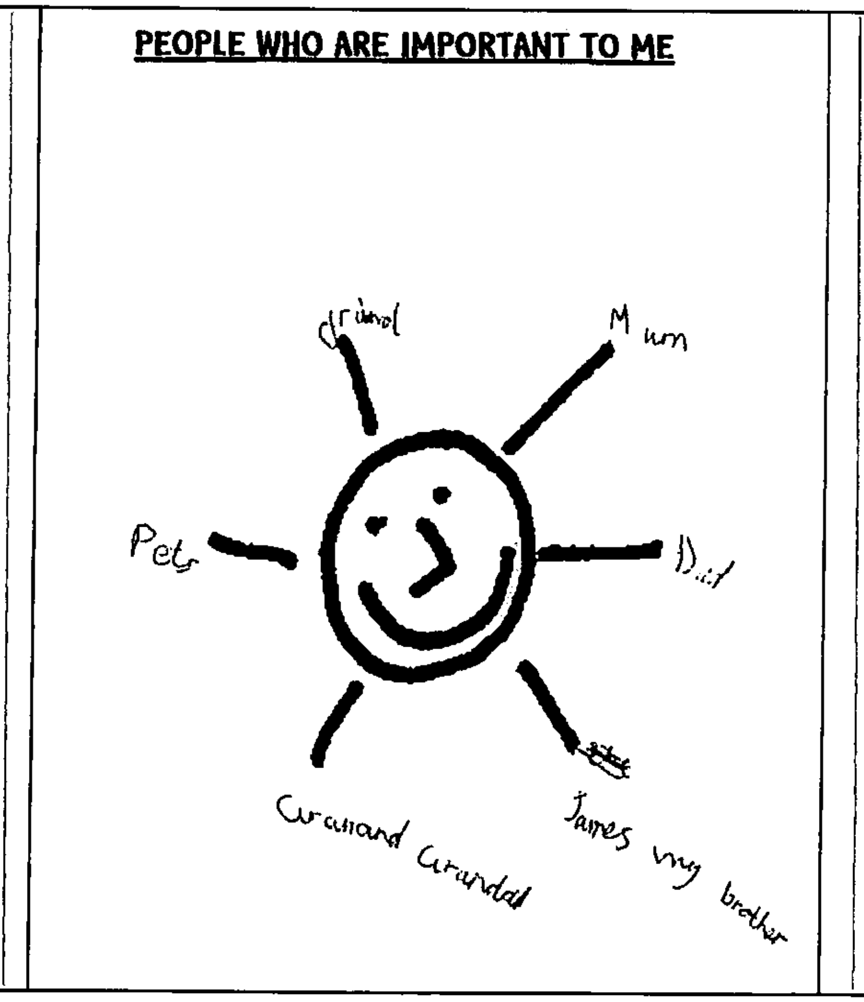


Figure 6.6 Activity by Milly

Other siblings were unable to visit for a variety of reasons. Maija's (30) account poignantly highlighted that she missed her two younger brothers whilst she was in hospital. Despite her father visiting and her mother being resident Maija mentioned twice in her interview that she "would like all her family to be here all the time". On exploring this further, her father commented that it would be preferable if Maija was in a separate room so he could bring the younger child in. He explained that "he would just destroy the room and disturb everybody. I daren't bring him in. I don't know what people would think", revealing parents' anxieties around censure by other parents' and professionals within the ward setting.

As in Milly's description, pets featured repeatedly in children's and young people's accounts of the things they missed. Children often expressed their desire for their pets to be with them in hospital by wishing for "a hospital that allows animals so my pets can stay with me" (Emily, (13) aged 12 years) and commenting that "I think that pets should be allowed. It's not right that your mum and dad can stay and not your pets" (Anna, (2) aged 7 years).

Alongside missing their parents, family and pets, children and young people also spoke of missing certain aspects of their home life including the comforts of home, their "own comfy bed and bed room" and having their own personal effects around them. It appeared that this added to children and young people's feelings of loneliness.

The separation from friends that hospitalisation incurred was highlighted by children and young people across all age groups. For example, those identified as being missed whilst in hospital included; "me friends and people at me nan nans. Yes, all my mates. Mainly all t'lads at the centre" (Isabelle, (20) aged 14 years). Others identified the feelings of "losing touch" that being away from friends brought about:

> "Well there's my best mate. I miss her a lot when I'm in here. She's been once to see me. I miss my fiancé loads as well. He comes in everyday though. I've got friends from where I live. They're the ones I do things with when I can. I hate not seeing them when I'm in here. I don't like missing out on what's happening. I feel right out of it" (Charlotte, (8) aged 16 years).

Despite the presence of parents' being very important to children and young people, others identified the particular significance of friends' visits:

> "We talk a lot and they tell me all the latest stuff about school. You know, who's going out with who, that sort of thing. Important stuff. They're more on my wave length as well. They know what music I like and so they bring their new CD's in for me to listen to and we swap magazines. You know, my grans are very sweet and they spoil me with lot of things but they never bring me stuff I like. And my mum and dad are like, "why are you so interested in hearing about so and so. They're not even in your class". They just don't understand what's it like to be 15" (Hannah, (17) aged 15 years).

Those children and young people with chronic illnesses resulting in spending prolonged periods of time in hospital spoke about the friendships these past admissions had brought about and described the informal support network that was in place. Again these friendships were of great significance and value:

> "Well I see the different people from clinic when I'm in here and that's always nice. It's good to see people and to catch up. ... We talk a lot about things we miss from the old days like missing the old nurses and that sort of thing. It's nice anyway to have someone to talk to. Especially when it's people who are going through the same thing and know what's it like" (Samuel, (41) aged 16 years).

Friends were clearly very important to children in hospital. In the period of preliminary observation friends were seen to visit often, although on the whole, these visits lasted for only short periods of time. Most often it was clear that parents, either of the child in hospital or the friend, remained at the bedside throughout the visit, thus children were very rarely left alone, although it was difficult to ascertain why this was the case. However, on the few occasions where friends were left together, children appeared to visibly relax and take on a different persona.

Children and young people described the companionship their parents, family and friends provided in order to counteract the adverse effects of being in hospital. These included "talking a lot, buying sweets and food and going downstairs together" (Stephen, (43) aged 12 years). For others conversation was an important element:

> "We just talk a lot really. I don't know. It just helps being able to talk to them and that" (James, (21) aged 12 years).

It appeared that the companionship provided by others was a valuable element in both reducing anxiety and providing security. Indeed, parents, family and friends were frequently referred to by children and young people as providing security. For example, Joshua (23) commented that:

> "It's really important that my mum's here with me. She's moved in with me. ... I'm in this huge building with people sticking things in my arms all the time. I only feel safe when my mum's here" (Joshua, aged 12 years).

At times security was provided by other children on the ward as the following account indicates:

> Maria: "Is there a time when you feel really safe when you're in hospital?"
> Sarah: "... when I'm really upset and they go after me and I lock myself in the toilet. [Name] used to do that all the time, go after me and make sure I was OK".
> Maria: "Is [name] one of the nurses?"
> Sarah: "No, he's in bed three. He's in hospital like me" (Sarah, (42) aged 11 years).

This provision of emotional support by family and friends seemed essential as both preliminary observation and children's and young people's accounts indicated that on occasion, nurses were unable to provide this element of support. This will be described further in Chapter 7 alongside children's and young people's direct experiences of nursing staff. In the next sub theme I described children's and young people's experiences of the multiple professionals they came into contact with in the hospital setting.

Strangers and other people you don't know

The period of preliminary observation revealed that many professionals were involved in each individual child's care. For example, children and young people were frequently observed to have between two to three doctors, two physiotherapists and between five to six nurses involved in their care each day. Often other professionals such as dieticians, social workers, radiographers and other members of staff would also have some contact. As a result of this, children and young people appeared to find it difficult to build relationships with members of hospital staff, particularly nurses, who were the staff group they came into contact with most frequently. Children and young people often spoke of seeing "different nurses, different, different nurses all the time". For one young person the difficulties inherent in developing relationships with nursing staff were clearly articulated:

> "You don't get to know the nurses like you used to be able to. Like, you can't make friends with them and sort of get them to be your friend and you be their friend. ... There's just so many of them and you might see one nurse one day and then never see them again. Even when they might be on the ward when you're still here, they probably won't look after you again" (Hannah, (17) aged 15 years).

It would appear that being unable to build relationships with members of the ward staff, particularly the nursing staff, compounded children's and young people's feelings of loneliness and isolation. For example, Yasmeen (45) commented that "when my mum's not here I don't feel so lonely if I know the nurse who is looking after me. But I don't really know any of the nurses this time" (Yasmeen, aged 8 years). For Lydia (29), admission to the study hospital contrasted negatively with experiences in other hospitals as she and her mother explained:

> Lydia: "This hospital is lots different to my other hospitals" (previous hospitals).
> Mum: "Yes. We'd got used to the hospital that we've been in because Lydia had been in there since she was three weeks old. It was like going to see your friends."
> Maria: "Because you knew everybody?"
> Lydia: "One of them hospitals. I didn't actually go to stop in it, did I, but the nurses didn't seem very nice because I missed my own nurses. But I'd been going to that other hospital for ages" (Lydia, aged 10 years).

In the next sub theme I describe the ways in which children and young people experienced physical isolation.

Experiencing physical isolation

Children and young people appeared to suffer effects of physical isolation due to being in the hospital setting. Many children and young people indicated that they found it difficult to make friends whilst they were in hospital.

> "It's difficult to make friends here. Like my friends that have CF [cystic fibrosis] like me, I know them but when we're here together we either have to be in cubicles or we're not allowed to be next to each other or opposite each other if we're in the same bay. They get worried about us passing bugs on to each other. Well, we do cheat a bit and talk to each other when we can get away with it, but we're not supposed to. Other people on the ward don't want to be your friend either because you've got CF. They see you having physio and catch on to what you've got. My mates from home don't like to come in either because they're worried about picking things up as well. It can be right lonely" (Hannah, (17) aged 15 years).

At times children and young people were isolated in separate rooms due to being infectious or at risk of acquiring infections from others. This compounded feelings of loneliness and isolation as children and young people described being in cubicles "for two or three days and didn't see anybody. Nobody came in at all" (Isabelle, (20) aged 14 years). For others, the "... cubicles can be very lonely. My family all work and can't get in very often so I might not see anybody all night" (Samuel, (41) aged 16 years). These feelings were reinforced by other accounts of experiences of being in a cubicle:

> "When I was little I used to hate being on my own. It used to make me cry 'cause I was so lonely. Like if my mum couldn't come I'd just be in a room all day on my own and no one could come in because they were all too busy. But now I'm older I'm not so bothered. I guess I've just got used to it" (Charlotte, (8) aged 16 years).

Isabelle described the physical effects of feeling lonely by saying that:

> "It really gets boring when you've got nobody coming in and talking to you. You fall asleep and it's no good falling asleep because then you don't sleep at night" (Isabelle, aged 14 years).

However, being isolated in a cubicle was not always the determining factor for children being unable to socialise with others in the ward. Stephen (43) commented that:

> "I like being in a room by myself. I've been on the main ward before but I think it's difficult to make friends when you're here, you know, in hospital. When I was in a bay before I didn't really interact with the other children so I don't think it makes a lot of difference really" (Stephen, aged 12 years).

It appeared that children and young people experienced feeling intensely lonely and isolated throughout their time in hospital. Isolation was perceived as being social, psychological and physical. Feeling lonely and isolated, often as a result of a disruption to normal friendships, resulted in children and young people feeling disconnected from their normal companions and support networks. This added to feelings of uncertainty and anxiety.

For children and young people it appeared that being uncertain resulted in being afraid and feeling powerless. The already existing fears and anxieties due to being in hospital added to the different nature of the environment and meant that feelings of loneliness and isolation were heightened further. It appeared that hospitalisation overwhelmingly disrupted children's and young people's lives. Disruption occurred as a result of being in the hospital setting itself as a result of the loss of normal daily routines and activities and separation from family and friends. The unknown and different nature of the hospital setting further added to the disruption whilst the inflexibility and uncertainty of the ward social order negated against children's and young people's usual everyday routines and led to a lack of control and further feelings of powerlessness. Feelings of loneliness and isolation impacted further upon these feelings.

However, children and young people were active participants within their experiences, undertaking certain actions to deal with the associated fears and feelings of uncertainty and powerlessness that being in hospital incurred. These will be discussed in the next theme.

Theme 4: Restoring equilibrium

As discussed, children and young people appeared to experience disruption and powerlessness whilst they were in hospital. However, rather than merely accepting this, children and young people demonstrated their agency by undertaking certain strategies in order to regain a degree of control whilst they were in the hospital setting. These strategies encompassed a range of actions and ways of thinking about the hospital admission in order to redress the imbalance of power and to attempt to restore equilibrium.

It appeared that restoring equilibrium reduced the disruption and powerlessness experienced by the children and young people. This suggests an important aspect to children's experiences in terms of their agency and active participation within their hospital stay. Indeed, for children and young people restoring equilibrium appeared to encompass acquiring optimism in the face of adversity. Children and young people both identified and actively exploited the positive aspects of being in hospital such as resting, relaxing and opportunities for play. For instance, Joshua, (23) aged 12 years, reported that one of the best parts about being in hospital was "getting to stay in bed and relax". Similarly, Grace (16) commented that "it's good when you're in hospital because you get to play with the toys and do other things that you don't have the time to do at home" (Grace, aged 6 years). For others, this extended to enjoying the undivided presence of family and friends by "getting spoilt by everyone. Especially when they bring me KFC in" (Stephen, (43) aged 12 years).

Whilst none of the children and young people wished to be in hospital, accepting the need to be an in-patient due to being ill was a common theme throughout. Acceptance of the negative aspects of the ward setting was frequently termed "getting used to" and "going along with" was referred to by the children and young people in a variety of ways and degrees. For example, James (21) commented that "it was boring for the first day, but I got used to it" (James, aged 12 years). Meanwhile for others, the disruption of treatment was accepted in order to get better and return home.

For some children and young people, being an inpatient introduced a form of stability in that they understood the need for treatment that could be given only in hospital. Thus the majority of children and young people accepted being in hospital due to the need to get better. As a result, both getting and feeling better appeared to offer some stability to children and young people:

> "I know I've got to be here. I don't want to be but I need to have nebulisers and other stuff I can't have at home and if I want to get better, and I do, I have to have them" (Oliver, (35) aged 13 years).

Similarly, for children and young people, feeling less frightened or in less pain once undergoing treatment and when their condition was improving appeared to act as a form of stability. Consequently children and young people recognised that they were in "the best place" even if there was a resigned element to their acceptance:

> "Being in here is the best place for me at the moment, unfortunately" (Louise, (27) aged 16 years).

For children and young people suffering from chronic illnesses which necessitated encompassing and complex treatment regimes, the respite that the hospital setting offered from these was welcomed:

> "It gives you a rest from carrying out all the usual stuff at home like having to sort out medicines. It's good because I usually have to get up at 6 o'clock in a morning to get my IV's ready but here the nurses' do them and I can stay in bed. It gives my mum a rest as well as she doesn't have to do my physio" (Callum, (6) aged 15 years).

In terms of a self awareness of gaining control, the children and young people displayed an awareness of those instances when circumstances were out of their control and possibly out of the control of some staff members. This reflected a sense of children's and young people's maturity and both an awareness and acknowledgement of the constraints experienced by staff. At such times children and young people conformed to the expectations of the ward staff and setting.

Importantly however, on other occasions children and young people demonstrated instances when they had been able to influence circumstances and change them positively:

> "Well, [doctor] said that I couldn't go home for my sister's party because I was too ill and needed to stay in for treatment. I said "well look. My mum does my IV's at home and my physio. I'm only going to be at home for about four hours. What harm can it do?" Well, he backed down and I got to go home" (Callum, (6) aged 15 years).

Both promoting and influencing the presence of family, friends and individual routines appeared to reduce children's and young people's feelings of loneliness and isolation, in turn limiting the effects of disruption and powerlessness. Indeed, on occasions young people demonstrated their ability to reduce isolation in other children by looking out for them and positively responding to their situation. For example, during an interview with Malachi, (31) aged 13 years, he turned to his mother and pointed to the young girl in the opposite bed. He commented "look she's crying because her mum's just gone. You'd better go and sit with her". Malachi's mother went and sat with the girl until her own mother returned.

It appeared that children and young people attempted to restore equilibrium whilst they were in hospital in order to redress the imbalance caused as a result of the disruption and its associated powerlessness. This was achieved by undertaking a range of actions and harnessing ways of thinking positively about the hospital admission. Successfully restoring equilibrium acted as a counterbalance against the disruption and powerlessness experienced in the hospital setting.

Summary

In this chapter I have explored children's and young people's experiences of being in hospital. These have been presented in four themes; feelings associated with being in hospital, being in a different and unfamiliar environment, experiencing loneliness, isolation and disconnection and restoring equilibrium. Previous research presents fragmented findings reflecting the needs and experiences of specific groups of children and young people around ages and illness and it has failed to focus upon the wider hospital context, the originality of my study is its exploration of the experiences of a diverse group of children and young people within the hospital setting. Whilst previous researchers might view this diversity as being a weakness it actually more accurately reflects the experiences of many children and young people who are admitted to wards without specialist focus and whose periods of hospitalization are spent alongside children and young people of different ages and who have very different diagnoses and prognoses.

The study reveals that children and young people were fearful of being in hospital, particularly in relation to being separated from family and friends, fear of the unknown and undergoing treatment. These anxieties were heightened by the unfamiliar and different nature of the ward setting which was experienced as being uncertain and inflexible to children's and young people's individual needs. Intense feelings of loneliness and isolation leading to feelings of disconnection were experienced. Subsequently, children and young people overwhelmingly experienced disruption and powerlessness as a result of being in the hospital setting. Arguably these experiences could be heightened by the diversity of ages, care needs and illness experiences cared for in a shared environment. However, a range of strategies and actions were utilized in order to restore equilibrium and redress the counterbalance in power, thus emphasizing children's and young people's abilities as active social agents.

Whilst these responses to hospitalisation are perhaps unsurprising, what is novel about the findings within this chapter is the way in which they are linked and how very strong emotional responses and anxieties such as disconnection and isolation were mediated by active strategies and actions in order to restore equilibrium. The link between these two core areas has not previously been explored and presented across a range of children experiencing hospitalisation. This demonstration of the active use of social agency in children and young people in the hospital setting is new, adding to the body of knowledge in this field.

In the next chapter I present and explore the theme focusing on children's and young people's direct experiences of being ill and receiving treatment.

CHAPTER 7:
BEING ILL AND UNDERGOING TREATMENT

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> "It makes me sad when I have headache and tummy ache. And when I have a fit. It tastes horrible" (Harry, (18) aged 10 years).

Introduction

Children and young people described in depth their experiences of being ill and undergoing treatment. These accounts draw on experiences both specific to individual children and those which were central to many of the children and young people with both acute and chronic illnesses.

This chapter is comprised of four themes, some of which have sub-themes, as represented in figure 7.1. As described in Chapter 6, restoring equilibrium is presented as a recurring sub-theme within each of the findings chapters.

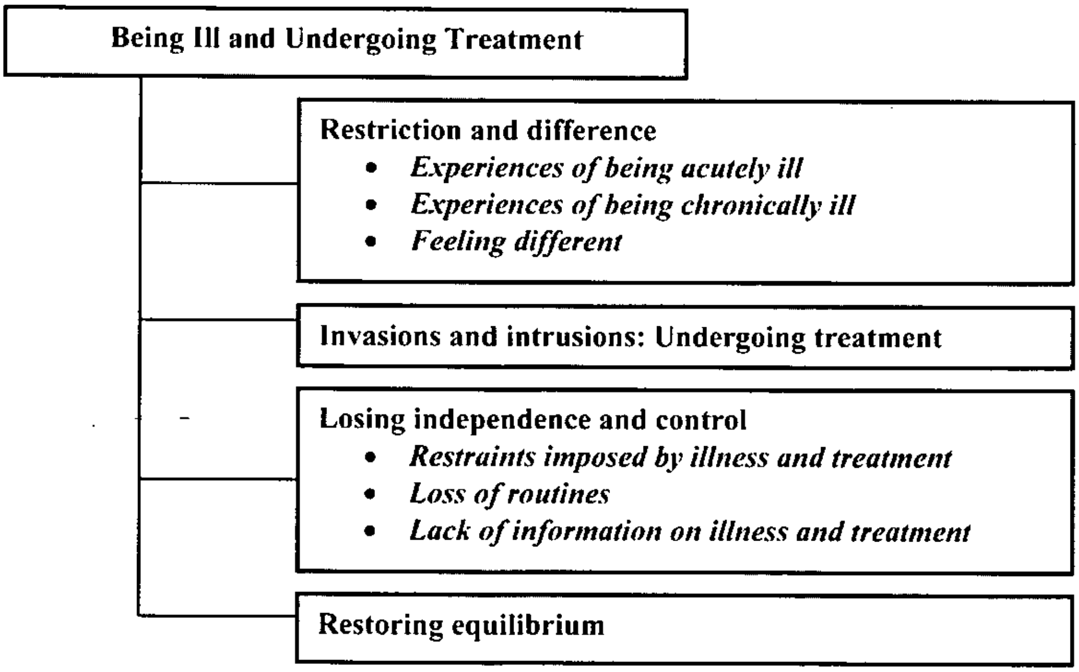


Figure 7.1 Outline of Chapter 7

Theme 1: Restriction and difference

Introduction

Children's and young people's experiences around being ill tended to focus upon the restrictions and limitations their illness imposed upon them, particularly in terms of illness related symptoms and pain. For children and young people with chronic illness, the dominance of ongoing illness management regimes appeared to restrict their lives on a daily basis. Furthermore, for this latter group of children and young people, looking and/or feeling different due to their illness was often a paramount factor in their experiences.

In this theme I explore experiences of being ill from the perspectives of both acutely and chronically ill children and young people and include their experiences of feeling different due to their illness.

Experiences of being acutely ill

Children and young people who had previously been reasonably healthy but then experienced an acute onset of illness predominantly described the restrictions that the symptoms imposed on them. Symptoms included, "feeling sick", "being sore" and "aching all over" and, as a result, "not being able to do anything". For example, Florence (14), suffering from a gastro-intestinal infection, had experienced severe vomiting over several days. When asked about what being ill had meant to her she commented that:

> "It has just been being sick (vomiting) over and over. I'd have given anything to stop being sick. At one bit I thought that it would never stop and that this would be my life now, just being sick for ever" (Florence, aged 10 years).

Children and young people spoke often about their body feeling very different to what it was like when they were not ill, using descriptors such as "my body doesn't feel like it belongs to me anymore. My legs feel like they are made of wood and I just have to sit down all the time" (Katie, (24) aged 7 years). Tiredness was a recurring theme encompassing terms such as, "feeling wobbly-kneed, weak like a kitten and dizzy as if the room is spinning". Children were aware that not only their illness made them feel ill but that treatment such as medications and surgery could contribute. Yusuf (46) for example talked about how the interventions caused symptoms that made him feel ill:

> "I felt really tired most of the time because I'd had an operation and I'd been quite ill. At one bit the medicines made me really sick and because of that and feeling tired I couldn't manage to do much other than lie down and watch telly" (Yusuf, aged 11 years).

Many children and young people spoke about being in pain when they were ill. Indeed for many, pain was the worst aspect of being ill. Georgina, (15) aged 5 years, suffered from headaches that resulted in recurring pain. She described this bodily hurt as, "my head hurts all the time and it makes my body hurt as well. It is the most horrible bit of feeling poorly I think". Meanwhile, for others pain was unanticipated and the unexpected nature of this was an unpleasant experience as Saira (40) explained:

> "I went to bed feeling OK and then woke up in the night with a pain in my chest. It felt like someone was jumping up and down on my chest wearing size 14 Doc Martens. It was honestly the worst thing I have ever felt in my entire life" (Saira, aged 9 years).

Olivia, (36) aged 7 years, illustrated the limitations and restrictions of having asthma when invited to draw a picture to depict her feelings about being ill (see figure 7.2). Her drawing, which portrayed her as looking sad, also incorporated her feelings about the restrictions having asthma imposed upon her. On talking about her picture, she described not being able to play with her friends due to feeling very tired and becoming breathless and the way in which this led her to feel frightened when she felt she was struggling to breathe.

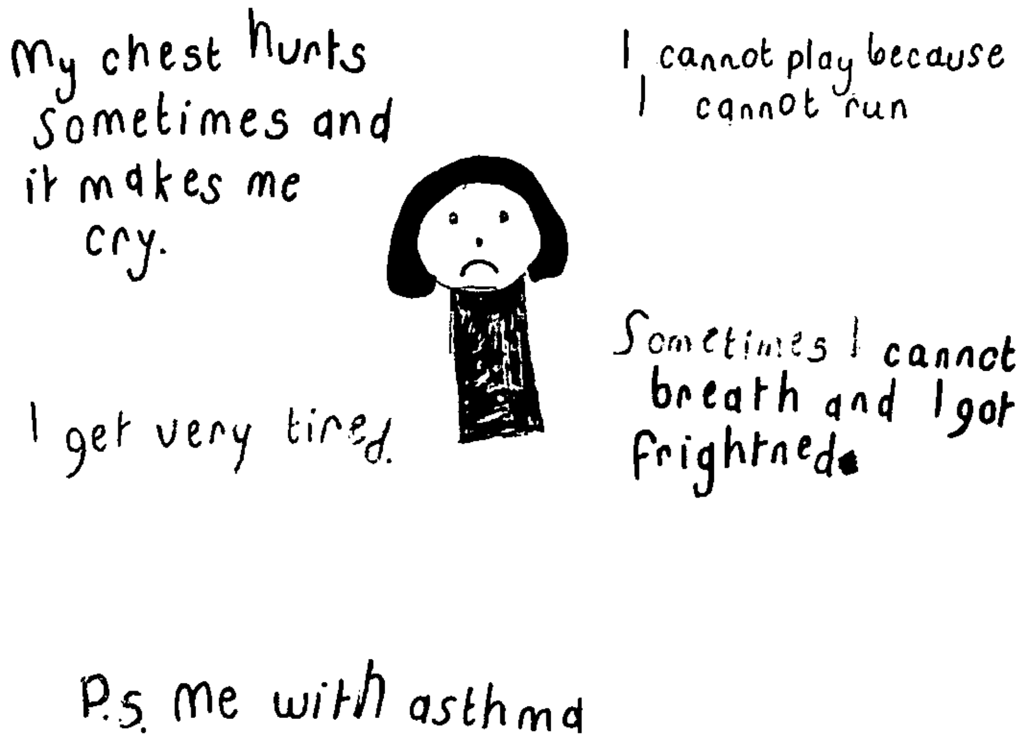


Figure 7.2 Drawing by Olivia

Other children and young people meanwhile related being ill to the feelings they experienced using descriptors such as "it makes you sad" and "unhappy". Once again these feelings reflected the restrictions imposed by being ill in terms of feeling miserable and isolated. The very unique nature of being ill was captured eloquently by Charlie (7) who commented:

> "Only you know what you feel like. No one else does and could ever know. I feel like I'm the only person in the world who feels like I do, like I'm all on my own and no one else knows" (Charlie, aged 11 years).

In this sub theme I have explored children's and young people's experiences of being acutely ill. In the next sub theme I describe the experiences of children and young people with a chronic illness.

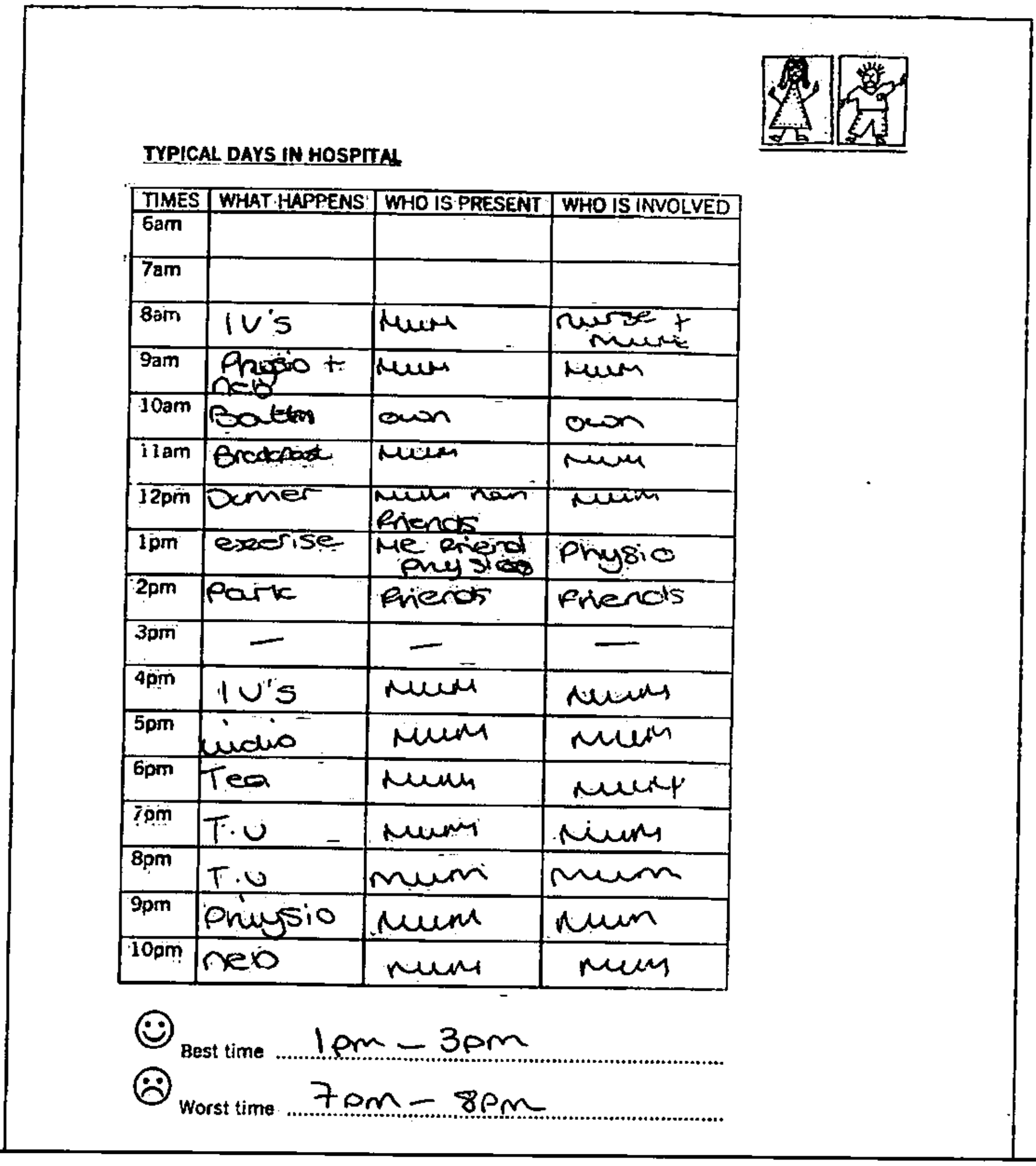
Experiences of being chronically ill

Children and young people with long term illness also described the restrictions imposed by being ill and its resultant symptoms in discussions around being ill. The following quotation from Charlotte (8), who has cystic fibrosis, describes the ways in which both the symptoms and restrictions of having cystic fibrosis impact upon her life:

> "I can't really do anything nowadays because of my CF. Like I can't do any gym stuff anymore, not even when I'm here with the physio because I just get too out of breath. I can't run or anything now. Even just walking to the end of the road makes me out of breath. My appetite's right poor as well. It has been for a while so that affects what I do with my fiancé or mates. It's no point me going out with them for a meal, not even to MacDonald's because it's a waste of money. I just feel right out of it not eating when they all are. Like they have to think about me all the time and walk slow when I'm there or not walk at all and have to catch a bus. I don't mind too much if it's just [fiancé] and me because he knows what's it like, but even though my friends know all about CF I still feel as if I'm a pain to them" (Charlotte, aged 16 years).

For children and young people with some chronic illnesses, the daily management routines necessary to remain well were integral aspects to their experiences. Once again these imposed many restrictions upon children and young people. For Isabelle (20), completing the "Typical days in hospital" activity (see figure 7.3) was valuable in revealing the way in which the daily management of her illness virtually dominated her whole day. As Isabelle explained:

"Well, I have sort of a routine for me. Antibiotics, nebulisers, physio, nebulisers, breakfast, medicines, antibiotics, dinner, medicines, maybe gym or exercise, tea, medicines, antibiotics, nebuliser, physio, nebuliser, supper, medicines and antibiotics. ... It just feels sometimes that that's all you do all day, every day. Especially when I've got say a bad chest" (Isabelle, aged 14 years).



TYPICAL DAYS IN HOSPITAL

TIMES	WHAT HAPPENS	WHO IS PRESENT	WHO IS INVOLVED
6am			
7am			
8am	IV's	Mum	nurse + Mum
9am	Physio + neb	Mum	Mum
10am	Bath	own	own
11am	Breakfast	Mum	Mum
12pm	Dinner	Mum nan friends	Mum
1pm	exercise	Me friend physio	Physio
2pm	Park	friends	friends
3pm	—	—	—
4pm	IV's	Mum	Mum
5pm	audio	Mum	Mum
6pm	Tea	Mum	Mum
7pm	T.V	Mum	Mum
8pm	T.V	mum	mum
9pm	Physio	Mum	Mum
10pm	neb	Mum	Mum

☺ Best time 1pm – 3pm

☹ Worst time 7pm – 8pm

Figure 7.3 Activity by Isabelle

For some children and young people, periods when their illness had worsened necessitated in increasing visits to hospital thus leading to further restriction. This was clearly felt by Anya (3):

> "Since before Christmas I've been in and out, in and out. I've been in at least every couple of weeks. Like in for two weeks for IV's then home for about three weeks then in again for some more physio and IV's then home again, then in again. Even when I've been home, they wanted to see me in clinic like every two weeks. I feel like I've never been away from the place" (Anya, aged 15 years).

In this sub-theme I have described children's and young people's experiences of being both acutely and chronically ill. Children and young people illustrated the ways in which being ill led to feelings of restriction and difference. In the next sub-theme I elaborate further on experiences of feeling different.

Feeling different

Often children and young people with chronic or long term illnesses spoke about both feeling and looking different to their peers due to suffering from illness. These differences included scars, both loss of and increased weight, clubbed fingers, jaundice, difficulties in walking, ways in which management routines impacted upon daily life, technology such as naso-gastric tubes and being limited in the activities they could undertake due to their illness. This resulted in feeling self conscious as Stephen (43) revealed when he commented that he was glad that his mother was able to put his creams on as "I don't like anyone else to see my eczema. That's why it's better to be in a room by myself as that way no one is looking at me" (Stephen, aged 12 years).

Anya's (3) insight into her condition is revealed in the following extended quote through the way in which her hurt, sense of separation and how she has grown up with feeling different:

> "It's like everyone sees me as different to them because I've got CF. It's like ... well, I'm lucky because I've got some good mates who I've known for years. You know, two or three pals that I grew up with and I've gone to school with. They're right good. I think they understand what it's like because they've grown up with me and they've sort of always known me with CF. Like they did all the asking why I had to have loads of physio and take loads of medicines when we were what, six or seven. They like accept it now like it's just something that's part of me. But I've found it right hard ever since I went up to comprehensive school. All of a sudden I was in a massive school with loads of people I didn't know and then the bullying started. ... I've been bullied for the last what, four years, ever since going to that school really. It got so bad in the end that I had to leave. My mum took me out and now I have a tutor at home. ...Well really it's because I have CF. I'm different to them aren't I? When I started at that school I was right thin, more than I am now and so I used to get picked on because of being skinny. But then when I had to go on steroids I got right big and then they were taunting me calling me a fat pig. You see, there was no pleasing them. Like I can't go away with the school because no one knows how to do my physio and so I can't go. But like this lass who's one of the bullies were saying that it were because my mum and dad couldn't afford it. I stopped taking my medicines at school because the bullies were making my life a misery and I didn't want them to see me taking them. Once one of them grabbed my bag and emptied it out in front of everyone and all my medicines fell out. They were calling me druggie and all that. After that I stopped taking them to school. You know, they were only like antibiotics and that, things that I should have had at lunchtime. I think that's why my chest's got right bad. [Doctor] went mad with me for not taking them but he doesn't know what it's like to be called a drug addict and all that. It's easy for him to say sitting at the back of a desk. He doesn't know what it's like. Staying at home, it got me away from the bullies but I miss seeing my mates every day. I only see them at night now. The bullies win every time. It's like, yes you're different and that's your problem. Go away and be different somewhere else. It's nothing to do with us" (Anya, aged 15 years)[20].

For other young people with chronic illness, the ways in which necessary management routines intruded upon their daily lives resulted in feeling different from their peers who did not have long term illness. Callum (6), who has cystic fibrosis, explained:

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[20] Bullying is not the focus of the thesis but it was an aspect of their lives that some children revealed to me.

> "Before school I have to get all my medicines out because I have to have some when I'm at school. I have to have my inhaler as well before my physio. I'm supposed to have a nebuliser but I've not got time so I just have my puffer and then I have to have a nebuliser afterwards. Physio takes twenty minutes, less if I've laid in. ... It gets me down really. I wish I could just be like my mates and get up in the morning and not have to think about physio and IV's and nebulisers and everything else" (Callum, aged 15 years).

The interview with Charlotte (8), who has cystic fibrosis, particularly highlighted the restrictions and difference of living with a long term illness. Charlotte described her friends who had cystic fibrosis and whose conditions were deteriorating and some who were now seriously ill. She spoke at length about a friend who had died recently and how it had affected her and her friends with the same disease. This account provided a deep and moving insight into living with a chronic illness and Charlotte's and her peers' awareness of the fragility of life when suffering from cystic fibrosis.

In this theme I have described children's and young people's experiences of having both acute and chronic illnesses and the ways in which being ill led to feeling restricted and different. In the next theme I describe experiences of undergoing treatment.

Theme 2: Invasions and intrusions: Undergoing treatment

Children and young people with both acute and chronic illnesses often depicted treatment as being all encompassing, invasive and intrusive, encroaching upon all aspects of their experiences whilst in hospital. This resulted in feelings of invasion and intrusion. Alongside this, the intensity of feelings around being ill and undergoing treatment were often pervasive, permeating children's and young people's hospital stay. Oliver (35) described the relentlessness of treatment:

> "It's been oxygen all day for three days, two drips and nebulisers every five minutes. Or it feels like every five minutes" (Oliver, aged 13 years).

Hannah's (17) experience of persistent treatment related to the medication and continual presence of the nurses:

> "Well I suppose for me the main routine was the medicines, especially when I was ill last time I was in. Because I was on so many things I was having something every couple of hours or so and it just seemed to be nurses coming all the time with medicines" (Hannah, aged 15 years).

For other young people, the intensity of treatment was revealed within their experiences:

> "... I've come in for surgery. I had a colostomy formed about six months ago because of all the problems with my bowel. Now I'm going to have it reversed, you know, put back inside. I was in hospital for nearly four weeks when I had the first operation. I was really ill at first and had to go back in to theatre and then I had to go to intensive care afterwards. At first I had three drips and a blood transfusion, well two blood transfusions. I had one in theatre and one in intensive care. I was covered in wires – there were wires and tubes everywhere. I had a drain in as well. That was why I had to go back to theatre because there was too much blood in the drain. That was how the nurses could tell that there was some bleeding in my bowel. They were worried about my blood pressure as well so I had to have another drip to make my blood pressure go back up" (Leila, (25) aged 15 years).

Yasmeen, (45) aged 8 years, drew a picture (see figure 7.4) of a red cross, a needle and syringe, a medicine bottle, a mask and a bed with a sad, crying face on display to depict her feelings about being in hospital. On talking about her drawing she explained that this is "what I feel I'm like in hospital. It just seems to be medicine and horribleness all the time".

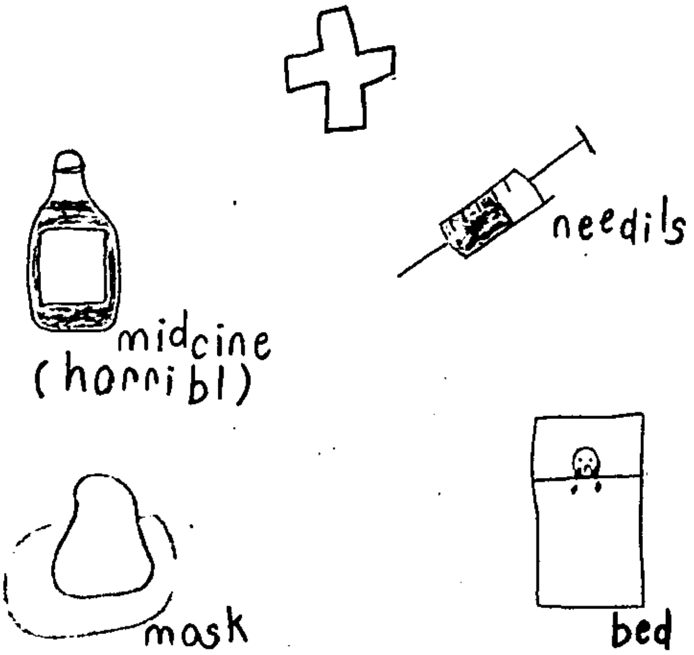


Figure 7.4 Drawing by Yasmeen

Older children and young people often talked about the physical effects associated with treatment. "The medicines made me feel so ill it was even worse than what I'd come into hospital with. I felt like I was dying. I had a bad reaction to one of the medicines and it was just so goddamn awful" (Louise, (27) aged 16 years).

Undergoing treatment also invaded many aspects of children's and young people's experiences by affecting their ability to move, play and eat. Abby, (1) aged 9 years, who was nil by mouth awaiting a visit to theatre at the time of her interview drew pictures of various foods entitled "food that I like" and "food that I don't like" when asked to draw a picture about being in hospital (see figure 7.5). On asking her to describe her drawing she explained that these were the things that she did like and did not like about being in hospital as she could only think about food as she was so hungry. For Emily (13), who has a chronic gastro-intestinal complaint, treatment at times necessitated undergoing long periods of time without taking diet, leading her to comment that, "I feel really happy when I'm allowed to eat proper food" (Emily, aged 12 years).

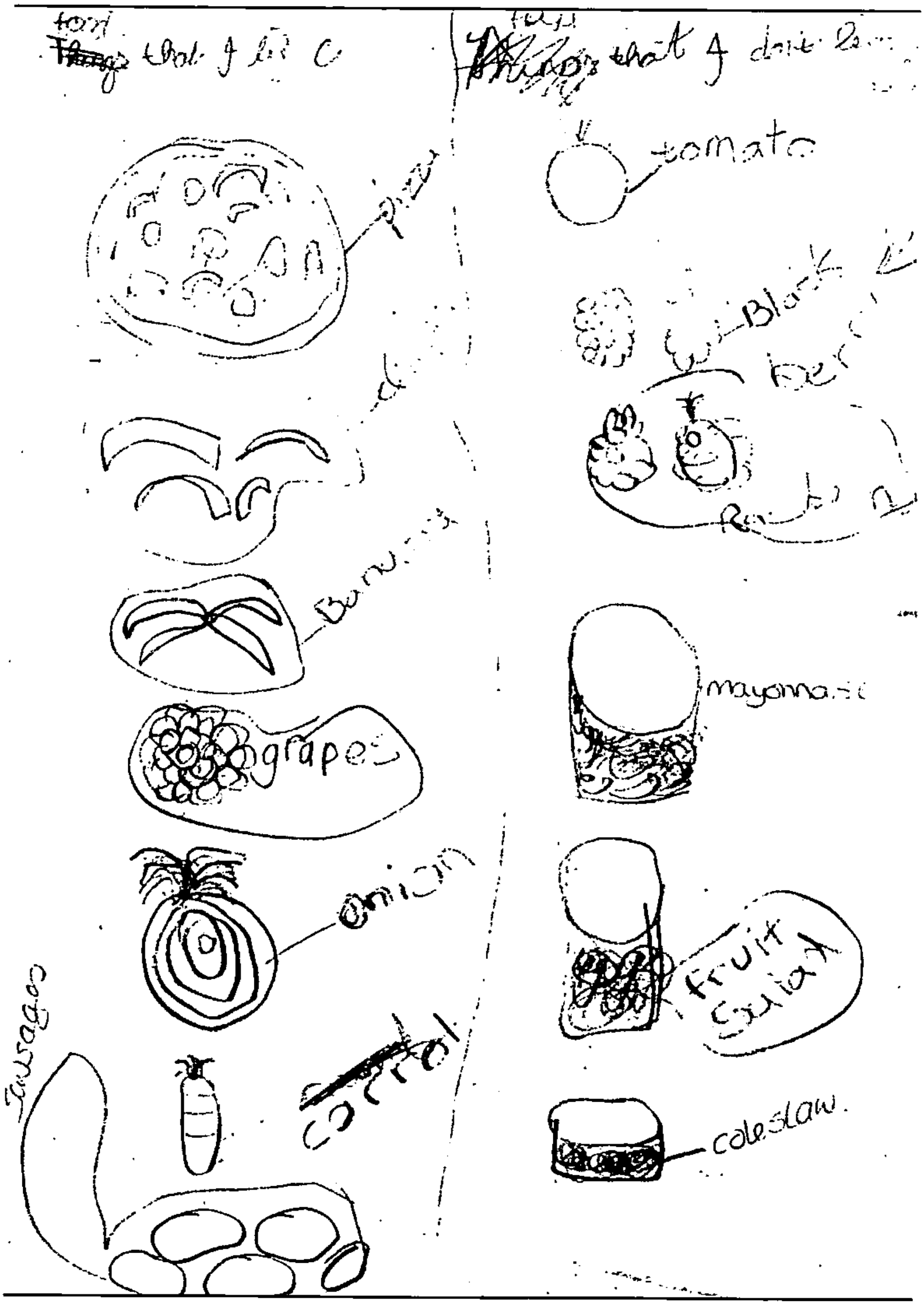


Figure 7.5 Drawing by Abby

There was often no respite from treatment which sometimes continued throughout the 24 hour period, thus intruding upon the children's lives both day and night as Oliver (35) explained:

> "You get woken up at night for medicines. You don't even get a break from it then" (Oliver, aged 13 years).

Often this routine throughout the 24 hours seemed inexplicable to the children and Louise (27) expressed a degree of exasperation when she explained:

> "…and at 06.00 every morning you get woken up by people walking round and sticking thermometers in you. That and that blood pressure thing squeezing your arm. Why on earth they need to do that at that time" (Louise, aged 16 years).

Children and young people in the study explained how feelings around being ill and undergoing treatment also invaded their experiences. Many children and young people described feeling anxious about undergoing treatment due to, for example, acquiring infections, the potential for mistakes being made and resulting in disfigurement and even dying. These feelings were invasive and intruded upon their time in hospital. For Abby (1), admitted to undergo surgery, fears around going to theatre were all-encompassing and she had a lot of unanswered questions:

> "I'm really scared about having the operation. Just the thought of having to lie on that trolley and then having to go to sleep. I keep thinking that I won't really go to sleep and they won't know. I saw that once on telly. And what if I never wake up? That's happens a lot, doesn't it?" (Abby, aged 9 years).

For Sarah (42), receiving treatment for an ulcerated leg, her anxiety was heightened because of her worries of possible disfigurement. As she explained:

> "I hope I won't end up with scars on my leg or this leg being shorter than the other. I hope the nurses won't make a mistake with my medicines and give me the wrong thing or anything. If that happened I might have to have my leg ampted [amputated] and then nobody at school would talk to me" (Sarah, aged 11 years).

Concerns around receiving "nasty, horrible medicines" featured centrally in children's and young people's accounts. For example, Emily (13), when completing the activity "Being in hospital makes me feel" described feeling sad when she had to have injections and medicine. Throughout the course of the interview it became apparent that Emily intensely disliked having to take medicines and she wished that there was:

> "a magic medicine that changed into the flavour you like the best" (Emily, aged 12 years).

Indeed, this was a common theme throughout the interviews with many children making wishes around the taste of medicines. Malachi's (31) one wish about medicine was that it should "taste nicer and not like sick" (Malachi, aged 13 years) and Joshua, (23) aged 12 years, disliked his medicine because it tastes "like treacle. It's really sugary".

Similarly, anxieties around receiving needles created feelings of trepidation and concern invading children's and young people's experiences. All the children and young people in the study described an intense fear and dislike of injections and needles, regardless of their age or hospital experience. Indeed, being afraid of needles appeared to be an all encompassing fear related to receiving treatment in hospital. Within the field of children's treatment, relatively few injections are administered nowadays as the intense fear experienced by children and young people is now recognised. However, the insertion of cannulas for the administration of intravenous medications seemed to be the intervention referred to when children and young people spoke about "needles". This is significant as Elijah, (12) aged 8 years, described the "worst bits" of being in hospital as the "needles". However, here Elijah's father probed his response as Elijah receives needles on a daily basis due to having diabetes and discovered that it was the cannula that Elijah was referring to. Despite this, many children and young people tended to refer to the cannula as a needle and depicted drawings of needles in their pictures. For example, Oscar (37) drew a picture of a syringe with a sharp needle when invited to think about having treatment for his Crohns disease (see figure 7.6). When talking about his picture he exclaimed in a loud voice, "it's gonna hurt because the needle is so so sooo big, so you'd better watch out" (Oscar, aged 11 years).

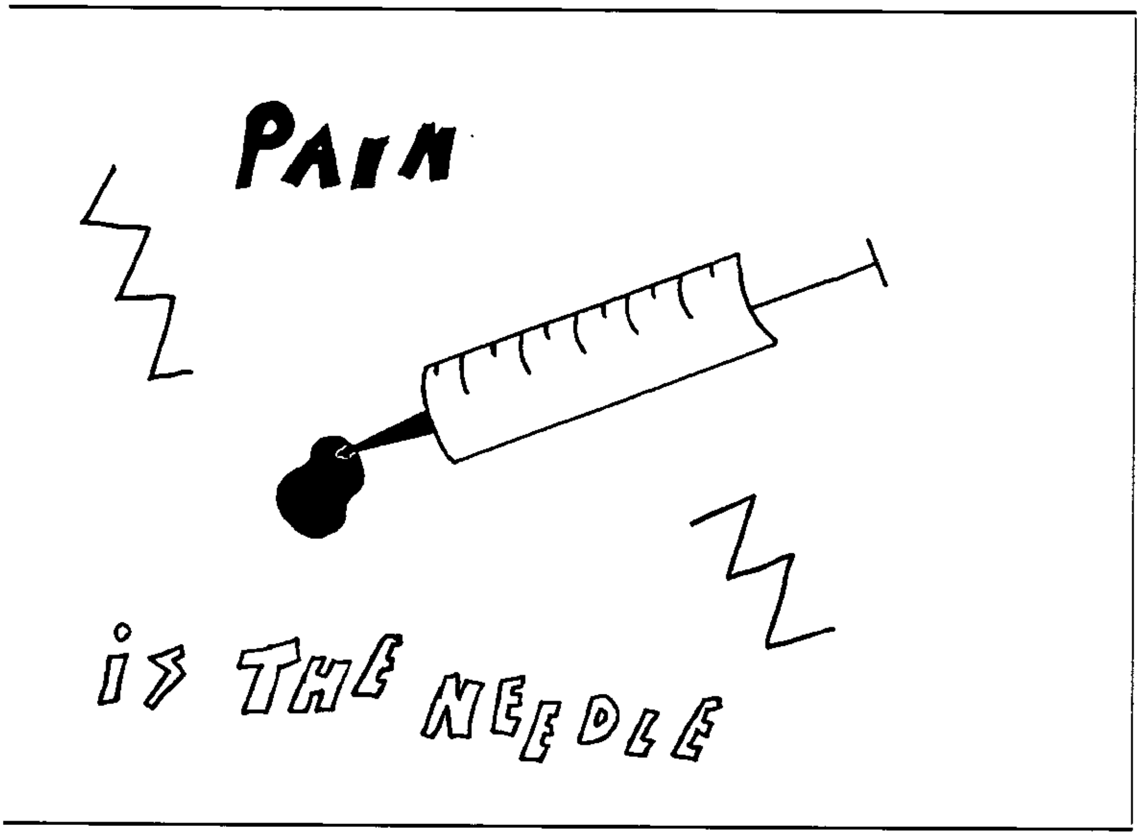


Figure 7.6 Drawing by Oscar

"Needles" figured in many of the accounts the children and young people gave, revealing both the pain and distress associated with them. Dominic (10) clearly described his hatred of needles:

> "Needles. I hate needles. I'm frightened of them. I've been prodded and poked that many times. I've had six needles. I had two needles in my arms and needles for blood tests and all that. I've had to have those thumb pricks as well. They do blood tests with those thumb pricks and I hate those as well. They hurt as much as having a needle in your arm" (Dominic, aged 13 years).

Olivia (36) was equally vehement in her dislike about needles but focused on their affect when she explained:

> "I was sad when the needle went in. It was horrible. ... I hate it when they miss and have to do it again. You feel like you want to die. It's like time stops and it lasts for ever" (Olivia, aged 7 years).

Children and young people spoke also about the sensation that receiving medication through a cannula brought about. Dominic commented that "it stings like hell. It feels like you're in hell when they put the needle in and then it's still hellish afterwards"

(Dominic, aged 13 years). The following account by Katie (24) is typical in explaining the pain and distress around this type of medication administration, although she clearly thinks she perhaps should be dealing with it better:

> "The yellow antibiotic is the bad one because it really hurts. It makes you cry and I'm nearly eight" (Katie, aged 7 ¾years).

Anxieties around being in pain were also central to children's and young people's feelings around undergoing treatment. Children and young people used descriptors such as "like a drill", "hammering away inside my head" and "like a knife cutting through my insides" to describe their pain. At times fears were exacerbated when pain had been experienced previously and these instances were recalled, as Dominic explained:

> "When I was in intensive care after I first had the accident, I was just in agony. It hurt everywhere. My arms, my legs, my stomach, my head. I just didn't know what to do with myself" (Dominic, aged 13 years).

For other children, fears around being in pain were heightened when they recalled previous delay in pain relief:

> "Yesterday night I wanted something (pain relief) and it took them about half an hour to get me something. And by the time they got me something my stomach ache had gone away. I said it doesn't matter now" (Lydia, (29) aged 10 years).

Experiences such as these led to another child, Sarah (42), making a wish so that "when you want something you could like say I want some [pain relief] and it's just like there ... like magic" (Sarah, aged 11 years).

For some children, undergoing treatment surrounded by others heightened their feelings of shyness and embarrassment. Joseph's (22) description reflected his feelings of self consciousness around other children's awareness of his treatment for asthma:

> "I feel a bit shy because the bay is so busy and I don't want to disturb everybody with the nebulisers" (Joseph, aged 10 years).

Many children and young people described feeling fearful about the conditions of other children. For Yusuf (46), this included other children having fits and the dilemma this created for him. Whilst he was clearly frightened he also expressed a sense of responsibility:

> "That little boy he keeps like having fits. He's alright and then suddenly he just starts like kicking and jerking all over. It scares me. I daren't look at him in case he does it, but at the same time I can't not look at him in case he does it and nobody else knows" (Yusuf, aged 11 years).

Leila's (25) account describes her concerns and anxieties around a severely ill child admitted to intensive care whilst she was a patient there:

> "One lad was brought in on an ambulance stretcher. You know the ambulance crew actually brought him up. He looked in a right bad way. I think he'd been in a car accident or something. He was strapped on to the stretcher and you could see tubes everywhere. His mum and dad came in and they were crying when they saw him. His mum ran off when she saw him. ... It's scary you know on intensive care. I think it's all the equipment everywhere and the nurses rushing about. ... It really scared me when the lad was brought in. It was the middle of the night and I was lying in the next bed while everyone was rushing about and I was thinking how sick he looked. It really scared me. I thought he's only a lad. He's even younger than me. What if he dies or something. I could tell that all the nurses were worried about him. I could tell by the looks on their faces and the way that they were rushing around. You know, two doctors were by him all night and that doesn't happen unless something is really wrong. I just laid there and felt really worried for him. And for his mum and dad too. ... And I thought please don't let him die. Not here in the bed next to me" (Leila, aged 15 years).

Leila's final statement "not here in the bed next to me" makes it abundantly clear how the drama was just too close to bear.

For children and young people suffering from chronic illness, feelings around their illness and treatment often tended to be in terms of the long term plan for their particular illness management. However, once again feelings around the long term often invaded and intruded into young people's lives as Charlotte's (8) account describes. For Charlotte, the futility of treatment for her cystic fibrosis was clearly recognized:

> "I'm in for IV's, two weeks worth of IV's. It's because my lung function's down. It's been down for over a year now. My peak flows have been bad for ages and they don't seem to be getting any better, whatever I do. I'm under [respiratory consultant] for it now; [usual consultant] has put me to see him about it because he does the respiratory stuff. I don't think he knows what to do though. Everything he's tried hasn't helped. My peak flows are still right down. I'm waiting now to go to [specialist centre] to be reviewed to see if I need to go on their transplant list ... Most probably I'd need a heart and lung. They'll do a load of tests when I get there, peak flows and more detailed lung function tests. They'll check out my heart as well because they think that my CF is putting my heart under too much strain. Of course my lungs are knackered with having CF" (Charlotte, aged 16 years).

Charlotte's account revealed that it was not the tests themselves that concerned her. In fact, Charlotte was more anxious about the results of the tests than having the tests themselves:

> "I'm not scared about having the tests. I've been in and out of hospital since being right small so I'm not scared of hospitals. I suppose it'll feel funny going to another one because I've only ever come here. I'm not scared of the tests either because I'm used to them now. I think I must have had everything possible done to me so I'm not right bothered. I suppose I'll be a bit worried about what they'll say to me afterwards because they're doing all these to see if I need to go on the transplant list. So it'll be scary to see what they say about my lung function and to find out how bad they think it is. Deep down I know I'll need a transplant one day, sooner or later. They might say I don't need one this time but I think I'll just get referred back again and again until in the end they put me on the list. I know that my lung function's not getting any better and I don't think it will now" (Charlotte, aged 16 years).

Thus for Charlotte, her own interpretation of her treatment had changed from chronic to futile. She defined treatment as being only to prolong her life:

> "I know that I'm never going to get better now and I do sometimes think what's the point of it all. The IV's and steroids don't do nothing now. They don't help me to feel better like they used to. There's no point really going though all the rigmarole of it all. ... It's like, well we know a lot of other people who've died don't we, like [names two children]. I guess it's just getting ready to be my turn now" (Charlotte, aged 16 years).

Charlotte's resignation and realisation is devastating because of the apparent acceptance she has of it being her "turn" soon.

This theme has described children's and young people's experiences of undergoing treatment. In the next theme I describe the ways in which children and young people believed that being ill and undergoing treatment led to a loss of independence and control.

Theme 3: Losing independence and control

Introduction

As discussed, being ill and undergoing treatment in hospital led to children and young people feeling both restrained and invaded. The restraints and invasions imposed by both illness and treatment resulted in them feeling a loss of independence and control whilst they were in hospital. However, a loss of control extended also to their sense of having insufficient information about their illness and treatment. For those with chronic illnesses, the disruption engendered in relation to their normal management regimes whilst in hospital and anxieties around transferring to adult services further added to a loss of control and independence.

In this next sub-theme I will explore children's and young people's perspectives of losing independence and control as a result of the restraints imposed by illness and treatment.

Restraints imposed by illness and treatment

Being ill often resulted in symptoms that led to a loss of mobility or ability to function as normal. As a result children and young people often experienced a loss of independence. Indeed, many of the children and young people recognised that they were ill because they were unable to carry out their usual activities:

> "I was bit out of breath when I was at school. It was on Monday. I couldn't do PE because when I tried to run I couldn't breathe very well. [Teacher] gave me my inhaler but it didn't work because I still couldn't run or do PE or anything. I had to go and sit in the Blue Room (medical room). ... When I got home I tried to take my dog for a walk but my breathing still felt funny. I couldn't even play with my brother and he's only two so then I knew something was wrong" (Anna, (2) aged 7 years).

The children and young people in this study spoke about the ways in which feeling ill impacted upon all areas of their normal daily lives including eating, drinking and sleeping. As Dominic (10) explained in relation to eating:

> "I've been feeling dreadful. I've not had any energy and I've not been eating properly. My mum says I should eat but when you feel like I do the last thing you want to do is eat" (Dominic, aged 13 years).

For others, being unable to play was an integral part of being unwell as Florence (14) explained:

> "It's horrible, horrible, horrible being ill. I can't do anything. Nothing at all. I can't draw and I can't play Barbie Connect Four" (Florence, aged 10 years).

Treatment itself often imposed restrictions upon children and young people, particularly where it necessitated being attached to equipment such as monitors or oxygen therapy as Poppy (39) described:

> "I can't draw or play games or nothing because of this silly thing (cannula) in my hand" (Poppy, aged 6 years).

This often hampered the abilities of children and young people to move and maintain their independence. As Joshua (23) explained:

> "This is the oxygen (points to mask and oxygen tubing on his pillow). I used to need that all the time but now I only need it from time to time. I have this machine on as well (points to monitor). ... It's so that everyone knows how fast my heart is beating. ... Because of the oxygen and this monitor I can't really do anything. It's just bed and toilet every day" (Joshua, aged 12 years).

Similarly Maija (30), explaining an instance where her mother had unplugged an intravenous infusion pump and wheeled it to the toilet, commented that "I wouldn't have been able to go to the toilet if my mum hadn't been here" (Maija, aged 9 years).

For some children and young people with chronic illnesses, technology was a part of everyday life in the form of ventilators and feed pumps. Callum, (6) aged 15 years, drew a picture of a nebuliser machine, a feed pump and his overnight ventilator in response to describing how it felt to have cystic fibrosis (see figure 7.7). On discussing his drawing he explained that there was often little difference for him between experiencing treatment at home and in hospital as he required fairly intensive treatment continuously. It is interesting to note in his drawing that whilst all the technology is drawn (all of it with attachments reaching out towards him) Callum has only positioned himself in the drawing with the word "me".

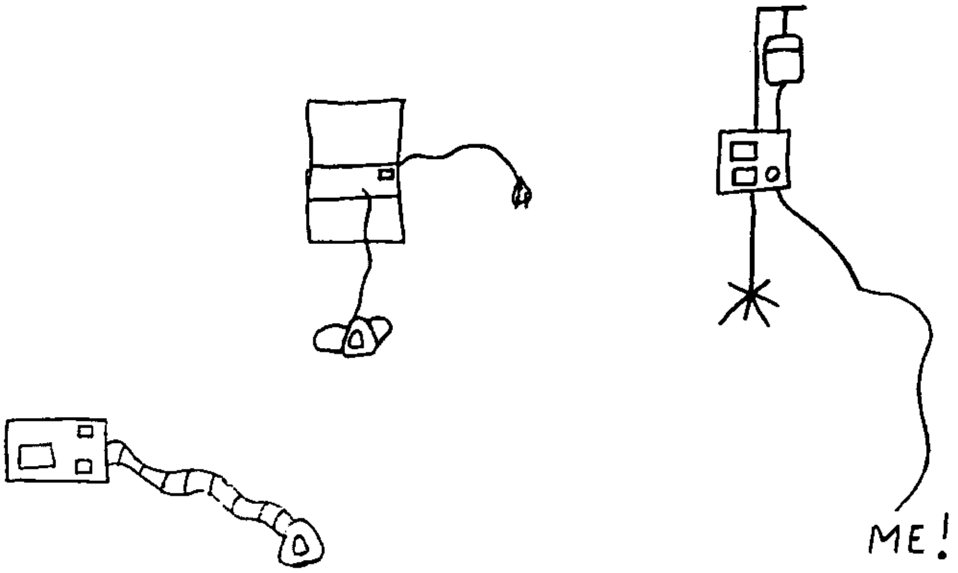


Figure 7.7 Drawing by Callum

For those children who required ventilation overnight at home a loss of independence could be detected. For example, Abby (1) commented that:

> "My vent [ventilator] is good because I used to be tired when I woke up in a morning but now I can sleep OK. It can be a pain though when it's being naughty and it keeps alarming at night. My mum once wanted to throw it out of the window. Even though I'm used to it now because I've had it for years and it's just part of me now, I still wish I didn't have to have it" (Abby, aged 9 years).

As a consequence, children and young people often became dependent on parents' and nurses' when ill and undergoing treatment. Needing assistance with normal daily activities such as washing and dressing often caused children, and particularly young people, to experience a loss of dignity. Many children and young people expressed concerns about being dependent on others and the subsequent loss of control felt when this happened. Joshua (23) commented that:

> "At the moment I can't get out of bed by myself because I need the oxygen. I have to have this machine on as well to check my oxygen levels. It's just a pain. I can't do anything at all without having to get somebody to help me and if my mum's not here I have to wait for one of the nurses to be free. Sometimes you have to wait for ages. It feels like I can't do what I want to do when I want to do it. And it makes me feel like I'm a baby" (Joshua, (23) aged 12 years).

This sub theme has described children's and young people's perspectives of the ways in which the restraints imposed by illness and treatment led to a loss of independence and control. In the next sub theme I explore how the loss of individual routines led to children and young people losing independence and control.

Loss of routines

Children and young people with long term chronic illness often had extensive knowledge and understanding of their disease and subsequent illness management routines. Many young people, such as Hannah (17), spoke about being the "experts" in their disease and its management and felt frustrated when this was not recognised whilst they were in hospital:

> "It gets me mad when people talk to you as if you're daft when you're in here (hospital). Me and my mum and dad do everything at home. We manage everything perfectly and then we come here and some stuck up so and so comes and sticks their nose in trying to make out that only they know what's the best way or right way to do stuff. It makes me so, so mad" (Hannah, aged 15 years).

Meanwhile, others felt that their treatment regimes were less well organised and executed in hospital than when they were at home by themselves and their parents. This led them to describe their frustration that their usual treatment regimes were disrupted through factors such as the late administration of medications leading to a delay in other aspects of care, as Samuel (41) describes in detail in the following extended quote:

> "I don't feel like I'm in control. Anything but! When I'm at home it's a pain to get everything myself but at least I know that I can just go to the cupboard and get what I need when I need it, whereas here, you just have to wait and wait till the nurses can fetch you stuff. You know, this is stuff you do at home everyday. And when they're busy, or if they forget, you're just waiting and waiting. Like at home I can fit everything into my day, I have my own routine. So I can plan everything around going to school or going out with my mates and still get my physio and nebs, IV's and stuff whereas here, some days I feel like I've not managed to do anything for me and I've still not fitted my treatment in properly either. ... Everything's to hand at home and you can just get it when you need it. You don't have to wait for anyone to fetch your stuff. My mum could just concentrate on me and do whatever I wanted and when I wanted it. The nurses here are too busy with everyone so you just have to fit round them and whatever they're doing. And everyone else on the ward as well" (Samuel, aged 16 years).

For other young people with chronic illnesses, the lack of choice around transferring over to adult services was another indication of losing independence and control as Charlotte (8) outlined:

> "I've been to look at the ward (adult transition ward). It's pants. It's just like a medical ward for adults with loads of geriatric patients. Like, I don't want to be in a bed surrounded by old people, all dying left right and centre. I suppose some bits are better though. Like there's a kitchen for patients to use which is something. ... I don't want to go. Or maybe I do. I just feel that I've had enough of this place (hospital) sometimes even though I never thought that I would ever say that. It's just that ... well when I was younger it would have been a big adventure but now, now I'm just tired and I'm just not bothered with it all. Anyway, it's not my choice is it? We don't get any say in any of it" (Charlotte, aged 16 years).

In the next sub theme I describe how children and young people believed that having a lack of information on their illness and its treatment led to a loss of independence and control.

Lack of information on illness and treatment

It appeared that children and young people in this study wished to be informed about their treatment in hospital so that they could be consulted in ongoing treatment decisions. This demonstrated their desire to have their opinions about their treatment respected and acknowledged. Many children and young people with acute or new illnesses described wanting information so that they were able to understand their illness and its treatment, be involved and prepare themselves.

The children and young people in the study described instances when they felt excluded from information about their treatment and subsequent decision making. Children noted occasions when medical staff ignored them completely when discussing their treatment with their parents'. As Paolo (38) explained in an indignant tone:

> "The doctors stand there at the bottom of the bed and they talk to everyone in the whole ward about me. That is, everyone except for me. Me who is ill and is the one who's supposed to be having all these wonderful things they keep going on about" (Paolo, aged 14 years).

On other occasions children described doctors speaking to them but using confusing technical jargon, thus leaving them feeling uncertain and perplexed. As Yasmeen (45) explained:

> "I didn't really understand what the doctors were saying. They were talking in long words and none of it made much sense. I think they thought that I was 28 and that I would know what they meant." (Yasmeen, aged 8 years).

Many older children and young people described a desire to be given more information about their illness and treatment. This group particularly wished to understand how treatment would work and any side effects that could be expected. For example, in children and young people with long term illnesses, concern was often paramount where the side effects of treatment might affect their physical appearance. Many young people, for instance, were anxious when taking steroid therapy due to the side effects of weight gain. This often seemed particularly significant to those with chronic illnesses as Isabelle (20) explained:

> "It would be good if they would tell you what the side effects of the medicines they give you actually are. Like when I were on steroids I couldn't stop eating and I were enormous. I wished that they (doctors) had told me that first. It matters to your life how things affect you. You see, last year I fancied him (friend) but because I were on steroids and right big he didn't want to know. Now I'm right petite he wants to know now" (Isabelle, aged 14 years).

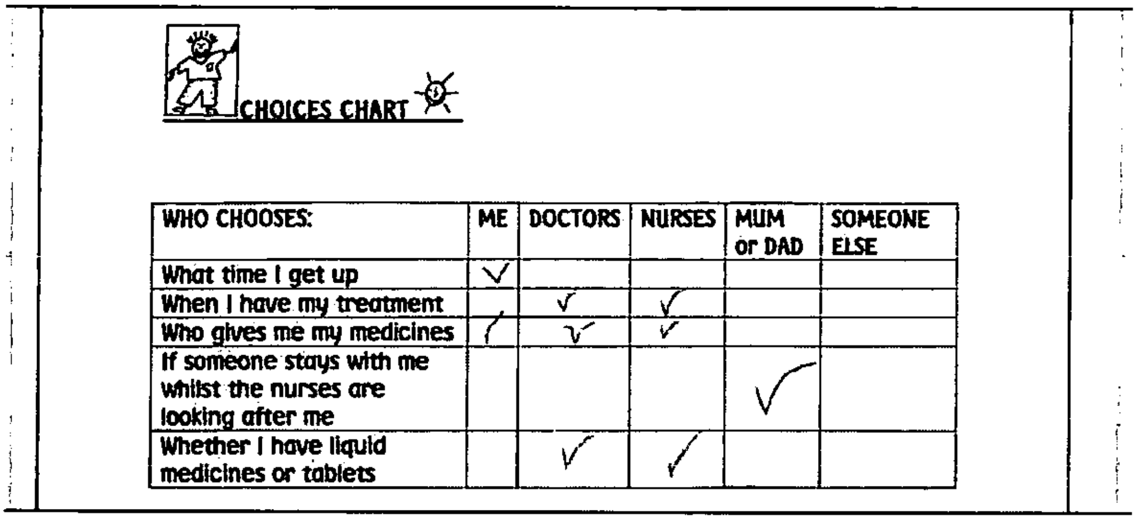
Information was also observed to be lacking prior to particular aspects of treatment where children may have welcomed explanation to reduce anxiety. One observation demonstrating this involved a member of medical staff attempting to take blood from Elijah (12) aged 8 years, without giving him adequate information regarding the procedure. Within this situation Elijah was clearly distressed and resisted having blood taken, resulting in him being restrained by a nurse and his parent as I noted in my field notes:

> [The doctor came into the bay and approached Elijah. He was sitting on his bed, reading a comic, with his mother at his bedside. He appeared quite settled and not at all distressed. The doctor is female, in her twenties. She said to Elijah, "hi there! I've just come to take some blood". Elijah immediately began to become upset. The doctor began to prepare her equipment; syringes, cannula and swabs. At this Elijah started to cry hysterically, looking and reaching towards his mother, shouting "I don't want it done, stop I tell you". The doctor said: "now come on, you've got to have it done. Let's just get on with it". Elijah pushed the doctor's hands away from him and began kicking with his legs. At this the doctor shouted a nurse over. The nurse tried to restrain Elijah but he was too strong for her. She asked his mother to help. The mother held Elijah's legs down (she appeared very reluctant to do this but did as the nurse asked). Elijah was still kicking and pushing the doctor and nurse away. The nurse leaned across Elijah, restraining him, and held his arm whilst the doctor took blood. Throughout the procedure Elijah continued to shout and cry. As soon as the doctor had taken the bloods she walked away. The nurse and Elijah's mum stopped restraining him. He shouted, "I told you I didn't want it done". He turned his back on his mother and began to sob. His mother looked very upset. She tried to comfort him. He pushed her away] (Fieldnote).

However, on other occasions prior to this I had observed Elijah have bloods taken and an intravenous cannula inserted without him becoming as distressed. However, at this time professionals had been patient with him, explaining the procedure and answering his questions.

The "Choices chart" (see figure 7.8) was valuable in encouraging Milly (33) to think about the choices offered to her within hospital. As can be seen, many decisions around treatment were made by medical and nursing staff in Milly's opinion with her only being given a say in who gave her medicines. Milly confirmed this in her discussion:

> "Well most things the doctors and nurses sort out, like when I have my medicines and if they have to be tablets. I can sometimes choose for my mum to squirt the medicine in my mouth though. But maybe it's not a big thing for me to be able to decide on" (Milly, aged 9 years).



CHOICES CHART

WHO CHOOSES:	ME	DOCTORS	NURSES	MUM or DAD	SOMEONE ELSE
What time I get up	✓				
When I have my treatment		✓	✓		
Who gives me my medicines	✓	✓	✓		
If someone stays with me whilst the nurses are looking after me				✓	
Whether I have liquid medicines or tablets		✓	✓		

Figure 7.8 Activity by Milly

It appeared that both the restrictions imposed by being ill and the invasiveness of treatment resulted in children and young people losing independence and control whilst they were in hospital. Losing control unsurprisingly led to feelings of powerlessness. Similarly the restraints and invasiveness of illness and treatment disrupted children's and young people's lives. Meanwhile, lacking information on their illness and treatment led to uncertainty for children and young people. As described in Chapter 6, feeling uncertain often resulted in children and young people feeling afraid and powerless, thus intensifying already existing feelings.

In the next theme I will describe the strategies undertaken by children and young people in an attempt to manage the disruption and powerlessness that illness and treatment experiences in hospital brought about.

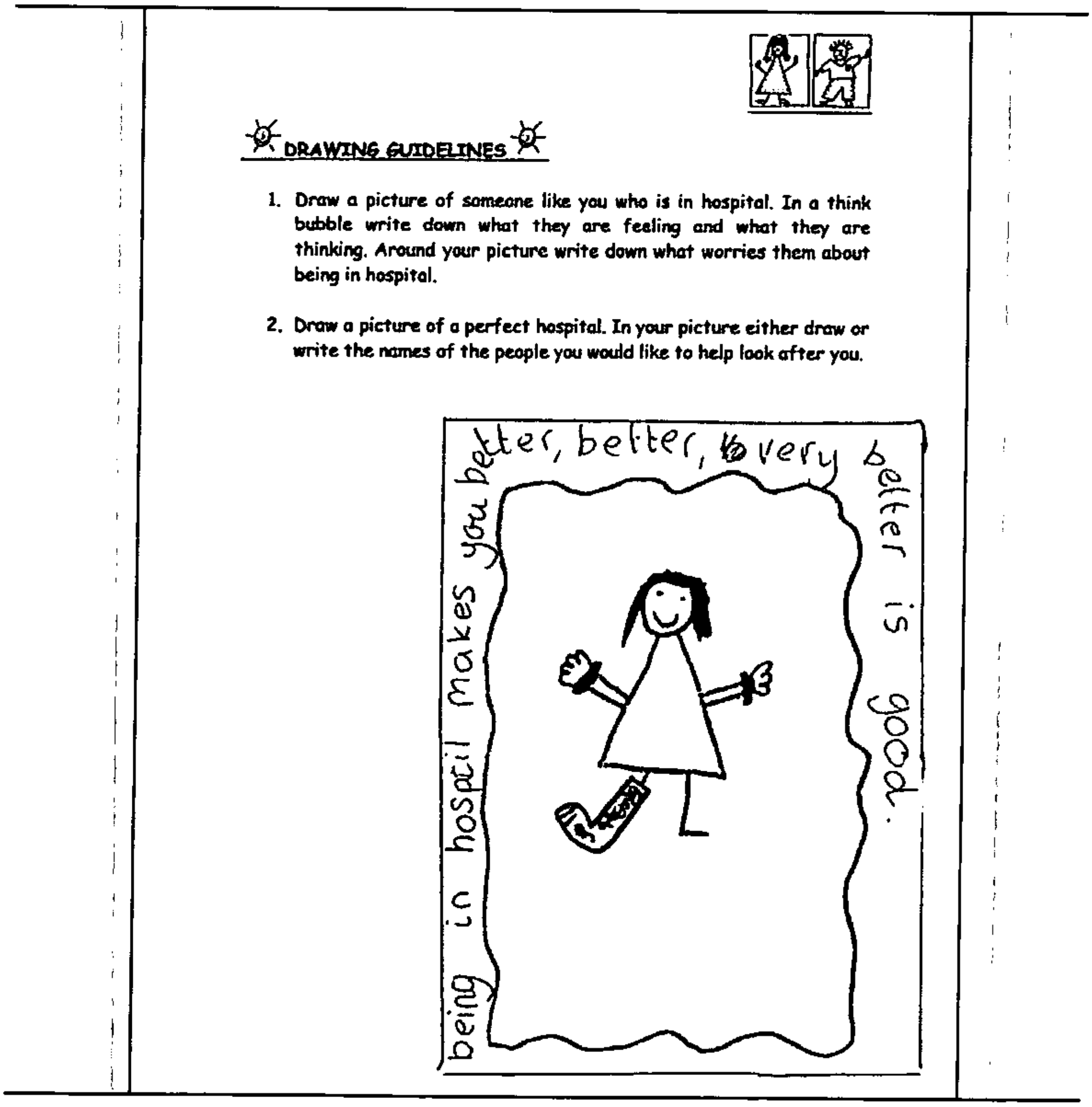
Theme 4: Restoring equilibrium

As described, children and young people expressed experiencing disruption and feelings of powerlessness and uncertainty due to being ill and undergoing treatment whilst they were in hospital. However, children and young people used a range of approaches in order to regain a degree of control within their situation and thus reduce the disruption and powerlessness experienced. As with their experiences of being in hospital (presented in Chapter 6), it would seem that the disruption and powerlessness experienced was diminished by regaining a degree of control and thus restoring equilibrium.

Many of the children and young people in the study spoke about restoring equilibrium by accepting their need to be in hospital in order to "get better" or "get back to normal". Sarah (42) admitted for treatment for an ulcerated leg explained that:

> "I enjoy being in hospital because you get better more. I would wish that I was a lot more better – my leg went. I wish I was rich, and well all my family were rich and I wish that my family would never ever get old or die or get poorly or anything, so if they fall down you could say a spell and oh yes – it just goes away" (Sarah, aged 11 years).

Sarah drew a picture of a girl with a happy face when invited to draw a picture of someone like herself in hospital, writing around the picture her thoughts and feelings (see figure 7.9). On being asked to talk about her picture she spoke about "getting better" and how that made her feel happy and less worried.



DRAWING GUIDELINES

1. Draw a picture of someone like you who is in hospital. In a think bubble write down what they are feeling and what they are thinking. Around your picture write down what worries them about being in hospital.
2. Draw a picture of a perfect hospital. In your picture either draw or write the names of the people you would like to help look after you.

being in hospital makes you better, better, very better is good.

Figure 7.9 Activity by Sarah

Other children also produced pictures around becoming well (see figure 7.10). This drawing by Emily, (13) aged 12 years, is a powerful illustration of a child's perception of the journey of getting better, from being ill in image 1 with bandages, pills, a sad face and injection to image 2 with bandages and a slightly sad face to image 3 with a smiling face, flowers and cards. In talking about her picture, Emily commented that:

> "I've drawn the bear that's feeling poorly as small because he's ill and the bear that's better as the biggest because he feels big and happy now that he's better" (Emily, aged 12 years).

Figure 7.10 Drawing by Emily

Some children and young people described the way in which getting better impacted positively upon their feelings as Florence (14) clearly felt:

> "When I was feeling poorly I couldn't stand having the antibiotic but now I'm better I don't mind it as much. All the things that felt horrible when I was ill don't matter so much now that I'm better and my stomach doesn't hurt" (Florence, aged 10 years).

Acceptance related to not only being in hospital but also to being ill. Children and young people described undertaking a range of interventions in order to feel better and thus regain some control over the circumstances in which they found themselves. For example, Elena (11) described accepting being ill in order to cope with feeling unwell:

> "You have to get used to it because that's just the way it is. It's no good being mad or upset about it or even feeling sad. At first I was but now I know that I just have to get on with it" (Elena, aged 14 years).

Children and young people often described dealing with pain by becoming stoical or self sufficient and, in certain situations, learning to anticipate pain or find comfortable positions. This enabled them to regain a degree of control, as Minna (34) explained:

> "My mum helps me to curl up on my side with my rabbit in my stomach and that helps a bit with the hurt in my side" (Minna, aged 5 years).

Others described using sensory and visual techniques to cope with the consequences of pain. For example Harry, (18) aged 10 years, spoke about lying still and focusing on sensory lights when suffering from headaches. Other children meanwhile used imagery when in pain:

> "I just close my eyes and dream of being on a beach and feeling warm and calm and taking deep breaths. I just think about the next breath and the next one and then I usually feel a bit better" (Libby, (26) aged 12 years).

Being ill was a unique experience for each individual child and young person. This was reflected in the contrasting strategies used by children and young people. For instance, whilst some children and young people described requiring the presence of parents and family when they felt unwell, other children preferred being alone and used this as a means of restoring equilibrium:

> "I just have to be by myself when my stomach hurts. I can't be with anyone else and I can't do anything, so that's what I do". (Maija, (30) aged 9 years).

For one young person, drawing comparisons with other children who had been in the intensive care unit with her, left her feeling more positive as she realised that her illness was not serious and her condition improving:

> "I just thought well I've never been poorly like he was (patient in next bed). I was so lucky in comparison. You know I've got a lot to be thankful for. I'll soon be better and I'll walk out of here. He might not do. Just be brave and put up with things and stop being mardy" (Leila, (25) aged 15 years).

Despite the children and young people in this study often describing treatment negatively, many spoke of restoring equilibrium by complying with necessary treatment regimes in order to return to health as quickly as possible. For example, many young people recognised that the treatment they were undergoing was essential and thus needed to be received and "got through". This was reflected in Malachi's (31) account:

> "It was really awful, a really awful time but I just thought lets just get it over and done with. There's no other way round it" (Malachi, aged 13 years).

One of the younger children, Violet (44), indicated her awareness of the necessity of treatment in order to get better:

> "It's rubbish and horrible when you have to have those head scans. ... I just try to be brave and go along with it although I'm not really brave. If someone could give me some like special magic dust so that I'd get better straight away, I'd grab it from them in a second" (Violet, aged 9 years).

It appeared that the children and young people within the study had varying experiences of being consulted and informed about their illness and treatment. As discussed, many children and young people described requiring information so that they were able to understand their illness and its treatment, be involved and prepare themselves. This was important if they were to regain some control over their illness and its subsequent treatment. Children and young people in the study described several ways in which they attempted to gain the necessary knowledge and information required in order to understand and actively participate in their illness management. Some described directly asking for information regarding their illness and treatment. For example, Grace (16) described asking nursing staff for information about the cause of her illness:

> "I had to ask the nurse why I was poorly because no one told me why I had to come into hospital, but it is because I've got a bug making me poorly" (Grace, aged 6 years).

Similarly Luke (28), admitted for orthopaedic surgery, explained that:

> "Like me, well I was strong and I asked the doctor what he was going to do to me because if you don't, you'll never know. No one tells you. They stand there and tell my mum and neither of us can understand what they're going on about, not even my mum and she won't ask. It's my leg though. I mean they could be going to cut it off for all I know. It's OK but I've just got into the first team (football) so I'm not going to say yes to that" (Luke, aged 10 years).

Children and young people also used other strategies. Joseph (22) described gaining understanding about his treatment by observing other children undergoing similar therapies:

> "When I first came in (to hospital) there was a girl over there in that bed and she was having nebulisers like I had in Casualty when I first was ill so I thought that she must have asthma like me. I just watched her to see what she did and looked at what happened to her so I could sort of work out what would probably happen to me. It has more or less been the same so far but she's gone home now" (Joseph, aged 10 years).

Gaining information about their illness and treatment enabled the children and young people to feel more involved and subsequently in control. In turn this seemed to reduce their fears and anxieties regarding being ill. At times, gaining information provided children and young people with the opportunity to make choices and decisions regarding their treatment. For example, Emily (13) described thinking over the choices in relation to her future treatment for Crohns disease:

> "[Consultant] wants me to have an operation really. I don't want it though. I mean if I have to have it in the end then I'll have to I suppose, but I'd rather try the medicines first. My mum wants me to have the operation though. [Consultant] says that I should have the operation too but he's talked to me about it all and says that it's up to me to decide. ... I think it should be up to me because it's my body. I know that it's an important decision to make. I know that I need to think about it and talk about it with the doctors and nurses. It's just that I hope that I won't have to have an operation in the end" (Emily, aged 12 years).

However, on those occasions when choices were offered, children and young people indicated the limits that existed in relation to these. For instance, Lydia (29) explained that being given a choice about whether or not to have bloods taken on a particular day resulted in having to have a finger prick instead and still needing to have the bloods taken the following day:

> Maria: "Do the nurses give you choices about how they do things?"
> Lydia: "Sometimes".
> Lydia's mum: "Yes, you got a choice about doing your bloods the other day".
> Lydia: "Oh yes, sure. They did them yesterday instead". (On following day thus bloods delayed by one day).
> Maria: "So you had some sort of choice and some say?"
> Lydia: "Yeah. Like I had a choice. I had a finger prick done because I didn't want to have my bloods done and that really, really, really hurt. So, children, kids, I've got to warn you that it does hurt! I don't really cry do I, mum, but I was like crying because of it. My mum asked for a sweet for me and I didn't like it so I gave it to my mum" (Lydia, aged 10 years).

Similarly, for other young people necessary treatment regimes resulted in limiting the choices available to them:

> Maria: "Do you think you're given some degree of choice then?"
> Callum: "Yeah, suppose so but because I have my own routine I still have to fit everything in so in another way I don't" (Callum, (6) aged 15 years).

Thus limitations were generally attached to having choices. However, it appeared that children and young people preferred to be enabled to make decisions, albeit limited ones, regarding their treatment as it provided important opportunities for reducing feelings of powerlessness.

There were some occasions when the children and young people demonstrated how they had successfully influenced their treatment. For example, Anya (3) described how negotiating the timing around her medication administration with nursing staff had enabled her to influence her treatment in order to allow her to leave the ward setting for a short while:

> "Like if me and my mum go over to the park I can have my IV's either before or after, so long as they know where you are and when you're gonna be back. It's got to be within an hour either side though. They weren't going to let me at first though. They said no. I kept on because I couldn't see the point of sitting here all afternoon doing nothing and so eventually they said that they'd let me" (Anya, aged 15 years).

Similarly, Charlotte (8) described influencing her treatment following a discussion with her consultant regarding a forthcoming test. She commented that:

> "I was supposed to be having a pH test but I just said to [consultant] why do I have to have it? What's the point of it? It's not going to change anything so why bother having it? Anyway he was a bit miffed and he huffed and puffed a bit but he couldn't come up with a reason why I had to have it. ... So he backed down in the end" (Charlotte, aged 16 years).

Children and young people described being better able to cope with the anxieties and fears that treatment heightened by having their parents present to provide support and comfort. For example, Florence, (14) aged 10 years, commented that she "wasn't as scared being with all those strangers" when her mother was present whilst she underwent treatment. Similarly, Charlie, (7) aged 11 years, explained that:

> Charlie: "My mum holds my hand when I have my antibiotics through the tube but the nurses have to give them."
> Maria: "Is it better when your mum stays with you when you have your antibiotics?"
> Charlie: "Yes. I like it better when my mum is with me. It doesn't seem to hurt as much."

Being able to better cope with these fears reduced the feelings of powerlessness experienced and provided an opportunity to regain control. Subsequently, children and young people described instances where they influenced their experiences positively by ensuring the presence of a parent during treatment episodes, as Dominic (10) described:

> Dominic: "When I was on intensive care I had to have a new needle in my arm one night because the other one had stopped working. It were the middle of the night and ..."
> Dominic's mother: "It were twenty past one and I'd just got to bed. I'd sat up with him till just after midnight".
> Dominic: "I wouldn't let the doctor put a new one in without my mum being there. I made the nurse go and get my mum".
> Dominic's mother: "Yes. She came and knocked me up and I had to get out of bed. Nearly fourteen as well".
> Dominic: "Well, I weren't having it put in without you being there. I don't care. I weren't having it done by myself".
> Maria: "Did it help you having your mum there?"
> Dominic "Oh yeah. ... Just because she were there really" (Dominic, aged 13 years).

Parental presence appeared to be especially important to children and young people when they felt ill or in pain. For some children, maintaining the presence of a parent at this time provided them with an opportunity to regain some control and thus restore equilibrium:

> "After I had my last fit my head felt like it was in a fire. I felt sick and I was sick and I hate being sick so I made my mum stay with me. I didn't want to be on my own" (Yasmeen, (45) aged 8 years).

For those children and young people with chronic illnesses, frequent clinic visits and stays in hospital often separated them from their unaffected peers. Conversely however, repeated hospitalisations provided the opportunity to meet up with a new company of friends who shared the same or similar life experiences due to having a chronic illness. It appeared that building relationships with this new group often provided a support network and a means of restoring equilibrium that was especially important and which did not always focus on illness as Samuel (41) explained:

> "It's nice when you come in (to hospital) and you see people that you know, like people who have CF like me and people like [name of friend]. He's got something wrong with his bowel so he's in and out (of hospital) all the time as well. I like having someone to chat to and it's good when you can talk to people that you already know. It's just easier when you're already friends and you can talk about stuff. ... It doesn't always have to be talking about being a cystic, you can sometimes just forget about all that and just talk about normal stuff like other lads of my age do" (Samuel, aged 16 years).

Within this new company of friends, children and young people seemed able to focus on similarities in their lives rather than their differences. Sharing these experiences appeared to be critical in developing a sense of identity and belonging and seemed to provide a feeling of acceptance and reciprocity as Leila (25) explained:

> "No one else knows what it's like to have what I have and to go through what I go through every day and especially when I'm ill with it. [Friend with same illness] does though. He's probably the only one. [Friend] is a bit younger than me but he's such a fantastic friend. I can ring him up anytime and he just understands because he knows what it's like when no one else does" (Leila, aged 15 years).

In this theme I have described the strategies undertaken by children and young people in an attempt to manage the disruption, uncertainty and powerlessness that illness and treatment experiences in hospital brought about. It appeared that undertaking these strategies enabled children and young people to restore equilibrium and achieve a counterbalance against the disruption, uncertainty and powerlessness experienced.

Summary

In this chapter I have explored the organising theme of children's and young people's experiences of being ill and undergoing treatment. I have presented these within four themes; restriction and difference, the invasions and intrusions of undergoing treatment, losing independence and control and restoring equilibrium. In comparison with the literature to date which has separated children and young people into disease groups, this study is unique through its exploration of the diverse illness experiences of children and young people as a whole which reflects the way in which children and young people actually experience hospital admission in many contemporary hospital settings.

The findings indicate that children and young people experienced restriction and difference due to being both acutely and chronically ill and encountered treatment as being invasive and intrusive. The restraints imposed by both illness and treatment led children and young people to lose independence and control due to the loss of individual routines and a lack of information on illness and treatment. This resulted in feelings of disruption and powerlessness. However, children's and young people's accounts reflected a range of actions and strategies that were utilised in order to restore equilibrium, thus redressing the imbalance in power.

Whereas previous research has shown that hospital and illness challenges children's sense of themselves, creating disruption and feelings of powerlessness, the findings from this chapter demonstrate the active way in which children and young people act to mediate potentially damaging effects. Importantly they act regardless of their diagnosis and length of experience or expertise with their illness. Thus, this work provides a novel insight into children's and young people's active and individual experiences of illness and its treatment. This, along with the findings from the previous chapter, which shows how children actively engage in actions and strategies, is providing the building blocks for new and informed ways of understanding children and young people's experiences of hospitalisation.

This chapter which has explored children's and young people's perspectives of being ill and undergoing treatment contributes to developing an understanding of experiences of care in hospital. I will explore these in the next chapter.

CHAPTER 8:
CHILDREN'S AND YOUNG PEOPLE'S EXPERIENCES OF CARE AND CARING IN HOSPITAL

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> Maria: "When you're in hospital do the nurses do some of the things that your mum usually does at home?"
> Lydia: "They do. I don't get my TLC that my mum gives me though. Tender loving care" (Lydia, (29) aged 10 years).

Introduction

Children and young people spoke at length around their experiences of care and being cared for within the hospital setting. These narratives highlight experiences, some of which are specific to individuals and others central to all children and young people, regardless of acuity or chronicity of illness. This chapter comprises of six themes, some of which have sub-themes, as represented in figure 8.1. Again, restoring equilibrium is included as a recurring theme.

Children's and Young People's Experiences of Care and Caring in Hospital

- **Being cared for by nurses**
    - *What nurses do to care for you*
    - *What makes a "good nurse"*
    - *Relationships with nurses*
    - *Experiences of care delivery*
    - *Value of nurses caring practices*
    - *Instances of "good" and "poor" care*
- **Doctors: Curing**
- **Being cared for by parents**
    - *Role of parents*
    - *Experiences of parents as carers in hospital*
    - *Importance of parents' involvement*
    - *Conflicts in care*
    - *Concern for parents*
- **Caring for oneself**
    - *Children's and young people's role in care*
    - *Co-ordinating care*
- **Experts in care: Children, parents and nurses**
- **Restoring equilibrium**

Figure 8.1 Outline of Chapter 8

Theme 1: Being cared for by nurses

Introduction

Children and young people described their experiences of being cared for by nurses during their stay in hospital. Their accounts included nurses' roles, the important attributes of nurses, building up relationships with nurses and the values they placed on nurses' caring practices. In this theme I explore these experiences from the perspectives of both acutely and chronically ill children and young people.

For the purposes of this thesis, care is defined as "a total way of being, of relating, of acting; a quality of investment and engagement in the other person" (Roach 1984).

What nurses do to care for you

Children and young people with both acute and chronic illnesses clearly defined the role of the nursing staff within their care. These activities included providing physical care and treatment, comfort and acting as an advocate. For example, many children and young people described actions undertaken by nursing staff to reduce pain or provide physical comfort as the following quote by Sarah (42) explains:

> "They help me with pain relief and that what I can't do, that sort of thing" (Sarah, aged 11 years).

Joseph, (22) aged 10 years, described how the nurses "make me comfortable and help me", whilst Harry (18) described how nursing staff had comforted him as he recovered from a convulsion:

> "[Nurse] sat with me because my mum wasn't there and I felt scared and my head hurt. She stroked my head for a bit and that helped because I'd got headache. Then she got me a pillow that wasn't hard and I went to sleep" (Harry, aged 10 years).

The nurses' role in providing physical care and treatment was a recurring theme throughout the accounts with children and young people describing how nurses "take my temperature and my blood pressure", "do blood pricks" and "test my urine". For example, Stephen (43) described the nurses' role in the delivery of treatment and physical care in the following way:

> "They [nurses] give you your IV's and they bring you your other medicines, the ones that you swallow. They make sure that your drip is working properly, ask if you're OK and if you want pain relief. They bring creams sometimes. They put clean sheets on my bed and they get food for me and bring it down" (Stephen, aged 12 years).

Indeed, for many children and young people the nurses' role was seen as essentially comprising the provision of technical or procedural elements such as the recording of vital signs. Like Stephen, many children on being asked about the nurses' role, described tasks that the nurses performed in relation to the administration of medications, testing blood sugars and performing urinalysis. However, children and young people clearly described that they expected the nurses to be able to look after them properly and "to do things right" as Libby (26) explained:

> "The nurses here know what they should do. That's good ... Well, it's a relief that they know. You wouldn't want to have someone looking after you that didn't know and kept getting it wrong, would you" (Libby, aged 12 years).

Children with acute illnesses often preferred the nurses to provide technical and procedural care as they viewed the nurses as possessing professional expertise and training in this area, highlighting their parents' lack of knowledge and competency within this. This was described by Milly (33):

> "Well, my mum looks after me really but she doesn't do my medicines and do a lot of the other things that the nurses do because ... well she's not a nurse and so she doesn't know what to do like they know what to do" (Milly, aged 9 years).

In comparison however, many children with chronic illnesses preferred their parents to provide all elements of their care. This included both technical and procedural care as often this was a role that they and their parents undertook at home and they trusted their parent's expertise. I will discuss this later within the chapter.

Nurses' role as advocate was clearly important to children and young people, regardless of age and extent of hospital experience, as Maija (30) clearly felt:

> "The nurses show you where things are and get you settled. A good nurse is someone who helps you out and takes care of you and is friendly" (Maija, aged 9 years).

For other children, the presence of nurses when alone was of paramount importance to them, as Minna (34) explained:

> "The nurse came and sat with me this morning because my mum had to talk to my dad on the phone and I was crying and didn't want to be by myself" (Minna, aged 6 years).

In this sub-theme I have described children's and young people's experiences of being cared for by nurses whilst they were in hospital. This included the actions undertaken by nurses. In the next sub-theme I describe those characteristics that children and young people believed made a "good nurse".

What makes a "good nurse"

In their accounts, many children and young people described the characteristics that they believed were essential to being a "good nurse". Many of these characteristics related to personality and encompassed attributes such as "bubbly", "lovely", "nice", "kind", "genuine", "make you laugh", "gentle", "helpful", "humorous", "friendly" and "patient". Indeed, children described "good nurses" almost entirely in terms of their attributes rather then their clinical competence. For Isabelle (20), having a "good personality" was an integral element of being a children's nurse:

> "Well, what are you a nurse for if you go on a children's ward to work with kids if you're not into looking after them. And why do you want to work on a children's ward if that's what it is, because to work with kids you need a good personality, you've got to keep them interested" (Isabelle, aged 14 years).

Abby, (1) aged 9 years, illustrated that she believed that "nurses and doctors are kind" in her drawing of a nurse (see figure 8.2). On talking about her picture she described her favourite nurse as being "nice and kind and she makes me laugh."

Figure 8.2 Drawing by Abby

Other characteristics associated with being a "good nurse" were related to behaviours and included elements such as "has time for you", "plays games" and "listens to you". For Lydia (29), a good nurse is "kind to you and plays games with you, anything like that. They make you laugh" (Lydia, aged 10 years). Similarly, Stephen (43) commented that, "I think that someone who can make you laugh is the most important thing" (Stephen, aged 12 years). For Charlotte, (8) communication was an integral part of nurse's work:

> "I think it's lots of different things really [to be a good nurse]. I think that communication is the most important thing though. You know, people who are able to talk to you, people who are genuine. I can always tell who's not genuine – it stands out a mile. I just can't be bothered with people like that" (Charlotte, aged 16 years).

Other young people described behaviours around treatment that encompassed the essential elements of a "good nurse". For example, Oliver (35) commented that a "good nurse" is:

> "Someone who is nice to you. Like if you've had something and it's made you sick they'll get it changed for you, you know, to stop you being sick" (Oliver, aged 13 years).

Similarly, Joshua (23) described nursing behaviours in relation to getting better when talking about "good nurses":

> "A good nurse is humorous and someone who is strict. Not strict, nurses aren't strict, but I mean someone who is able to help you get better by telling you what you have to do. Nurses that aren't strict are the best ones. There was a horrible one that was strict. She made me get out of bed" (Joshua, aged 12 years).

Thus for Joshua a "good nurse" would provide direction and guidance but in a kind and empathetic way. Indeed, children's and young people's accounts of "good nurses" revealed a strong association between behaviours and attributes. This was captured well by Florence (14):

> "Well, it wouldn't work if the nurses did the right sort of things but were horrible. That wouldn't be good at all, would it? They have to sort of do all the right things and be nice and kind all the time as well, so it all works out" (Florence, aged 10 years).

Some children and young people provided descriptions of their "perfect nurse", drawing on their own ideals rather than experiences to date. Milly (33) commented that "my perfect nurse would be kind and gentle and helpful" (Milly, aged 9 years). In a similar vein, Katie (24) explained that:

> "My bestest ever nurse would be so lovely. She would sit and play with me all day and we would eat chips and ice cream and not get told off. We would be like best friends or sisters. She would be the most loveliest person in the world" (Katie, aged 7 years).

Elijah (12) illustrated his thoughts around "perfect nurses" by writing down key characteristics helped by his dad (see figure 8.3). These characteristics included being "friendly", "happy", "kind" and "nice", "caring for poorly children" and "smelling nice". On discussing his views he commented that he felt that liking computer games and being good at them were important attributes he felt that nurses should have as so far "only one nurse has played on the computer with me and they were rubbish at it" (Elijah, aged 8 years).

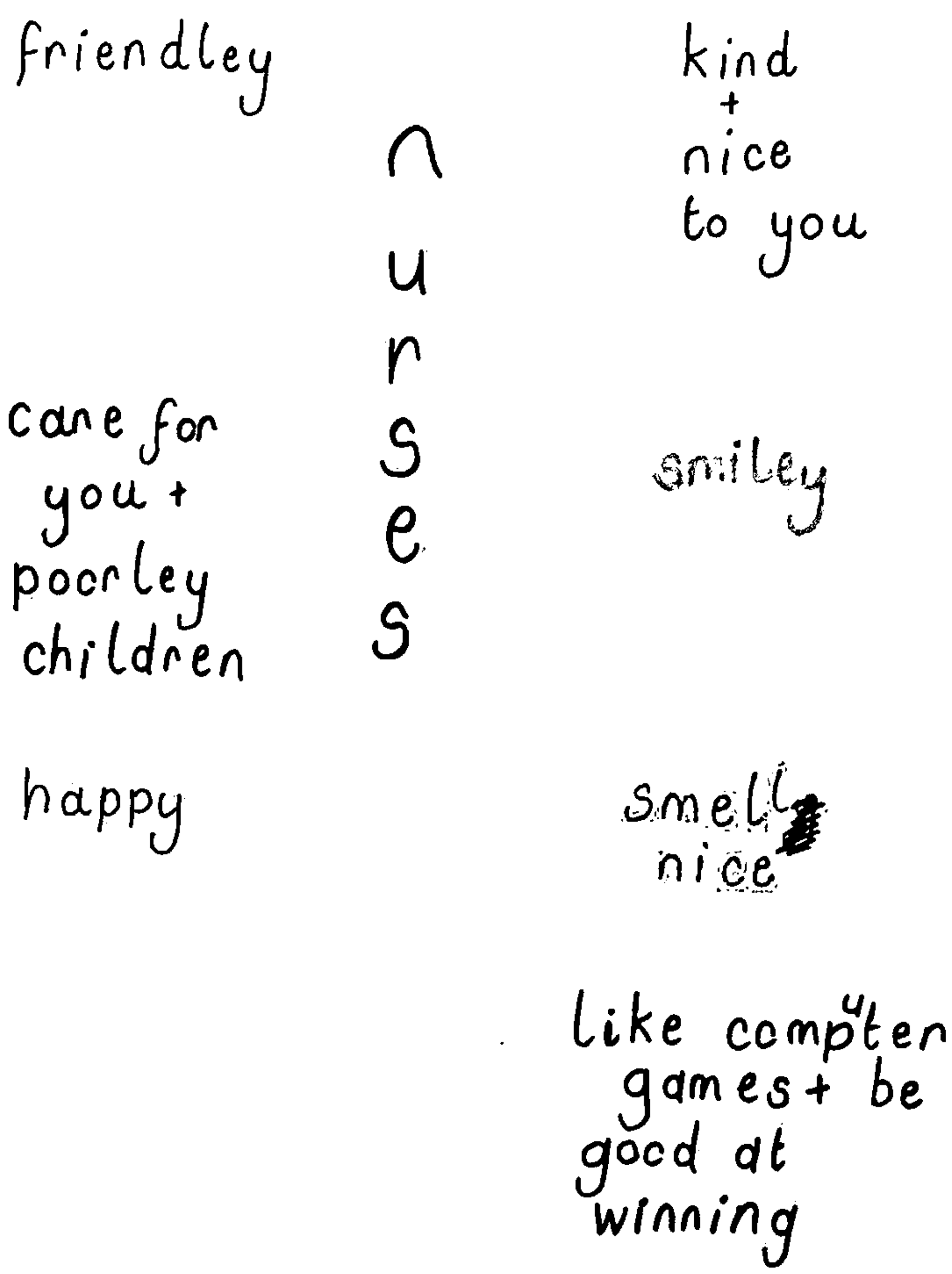

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Figure 8.3 Drawing by Elijah

Louise, (27) aged 16 years, identified the specific attributes she believed essential to being not just a nurse, but a children's nurse, as she describes in the following extended quote:

> "Like they've [nurse] got to be patient with little kids, haven't they? It's not like working with adults who you can just give stuff to. You've got to coax them and all that, get them to take their medicines and not be scared, that sort of stuff. I think that's all down to personality. Like, we've had some doctors that have worked on here, not really nurses but I'd say doctors and it just stands out a mile that they're not cut out for working with kids. They don't know how to talk to them or anything. Like the little kids, you can see they're scared and some people don't know what to do, how to be with them or that. You know they should really play with them a bit and stop them feeling as scared, but they just don't know how. Well, some of them don't even know how to talk to the parents, never mind the kids. Some others though are right natural. You can just see that they should work here. Like one of the nurses who left about a year ago, he was lovely. We all loved him and when we came in you wanted him to be on. He were right good with the little un's. I've seen kids come in absolutely terrified and he'd be fantastic with them".

Louise (27) then went on to elicit the important principles of having time for children and spending time with them that she felt were intrinsic to working with children that the male nurse had embodied:

> "I think it was the way he was altogether. He always had loads of time for everyone which is important. That matters a lot I think. It makes you feel as if you matter if people have time for you, or can make time for you. He had loads of patience and like put doing things with kids and parents as a big part of his job. Some doctors and nurses just want to sit at the back of the desk and drink tea. They don't like see it that it's part of their job to be with the kids and their mums and families. I mean, like they're really busy, I know that. But I just think that sometimes if it's a bit quieter, instead of sitting with the kids they just talk to each other and don't spend time with us. The good ones always do that. I think you probably have to be cut out to work with kids. It stands out a mile. You can see straight away if someone can do it or not".

She carried on by describing the differences in roles she believed existed between nurses caring for children and those caring for adults:

> "It's different to say looking after old people or even adults who aren't as scared as little kids. I think you have to have lots of patience with children and be prepared to act a bit like a little kid does. Well, not act like a kid but be prepared to play with them a bit if that'll help to get their trust and make them feel less scared. You can't be talking to them like they're 45 and just say here's your medicine, just take it. You have to be big enough not to feel stupid if you have to give it to their teddy bear first and that sort of stuff. To me, that's what's important. I mean, there's nothing good about being in hospital and if the nurses are horrible as well, it's just the pits" (Louise, (27) aged 16 years).

Children and young people believed that being cared for by a "good nurse" was essential in reducing feelings of anxiety. This is illustrated in the following quote from Emily (13):

> "I feel safe when I've got a nice nurse looking after me. You know, not so scared and not so on my own" (Emily, aged 12 years).

This theme has described the characteristics children and young people believed were essential to "good nurses". These included both personality attributes and behaviours both towards children and young people themselves and around treatment. Children and young people also outlined the specific differences necessary for those nurses working with children, as opposed to adults. Next I describe children's and young people's perceptions of their relationships with nursing staff in the hospital setting.

Relationships with nurses

Some children and young people spoke about positive relationships they had built up with members of the nursing staff and described the factors they believed were important in developing relationships. These included elements such as "sitting with me", "taking me downstairs to the café for crisps", "looking after me a lot", "knows me" and being "here all the time". For Stephen (43), a relationship had developed between one of the ward nurses and himself due to his being cared for by him previously within another setting. This individual knowledge of Stephen alongside the nurses' knowledge and understanding of his condition and treatment were clearly important:

> "I like [favourite nurse] most because I know him from clinic before he worked on this ward. He knows all about my creams and the other things I have to have for my eczema and so I can just let him put them on. Some of the other nurses don't know which cream goes on where and I have to tell them. It's just that I feel quite shy about my skin and having to have people I don't know putting creams on and it feels worse if I have to explain it all as well. I just prefer it when it's someone who knows me and what I have done" (Stephen, aged 12 years).

There was a strong association between nurses spending time with children and young people and the development of positive relationships. This is depicted in the following accounts. The first, by Lydia (29), is related to an instance where one nurse spent time with her by taking her away from the ward for a short while:

> "[Sister] and [staff nurse] have helped me most. They've just like made me laugh and [staff nurse] took me out for a walk in the park while she got one of the nurses an ice lolly. They feel like they're my friends somehow" (Lydia, aged 10 years).

Meanwhile, Emily (13) talked about a student nurse who had spent time with her when she was anxious and upset:

> "[Student nurse] is really nice. I feel like I know her the best. She came and sat with me the other night when I was upset. I was worried about having the operation and was crying and she came and sat with me" (Emily, aged 12 years).

One young person with a chronic condition described in detail the long term relationship she held with the nurse who specialised in her illness. The following quotation by Charlotte (8) describes the relationship built up over time, that existed between herself and the Clinical Nurse Specialist (CNS) prior to her leaving to take up another position:

> "I know loads of people with coming here from being little. You get to know the nurses best I suppose but you sort of build up long term relationships with people, but I'd say most definitely [previous CNS]. Like she were fantastic and I'd known her since I were little. She were on [old ward] and I sort of grew up with her. When she got that job that were brilliant and I loved her in that job. She were fantastic for me and I wished she'd not left. Like [present CNS], she's trying to get to know me but I'm distancing myself from her. I might be moving over to adult services soon, so I think what's the point of trying to get to know her when I might be going. She doesn't seem to realise that it takes time to get to know people. Like I'd known [previous CNS] for years and you just can't build up the same relationship overnight can you?" (Charlotte, aged 16 years).

In this sub-theme I have described children's and young people's relationships with nursing staff including those factors believed to be essential in developing relationships. In the next sub-theme I describe experiences around the delivery of care by nursing staff.

Experiences of care delivery

In this sub-theme I describe children's and young people's experiences of care delivery. This includes direct experiences around care provision including team nursing and allocation of nurses to children and young people.

Many children and young people described those factors that were detrimental to the development of relationships with nursing staff. Often these related to experiences around the delivery of care with children and young people describing elements such as being cared for by "different nurses all the time", "a high turnover of nursing staff" meaning that "we don't know them and they don't know us", "there's always loads of new nurses" and nurses not being able to spend time with children and young people leading to comments that "they don't come in to see us" and "the nurses don't spend time with us".

As described in Chapter 6, preliminary observation revealed that many nurses were involved in each individual child's care. As a result, care often appeared to be fragmented with a lack of continuity. For example, children and young people were frequently observed to have between five to six nurses involved in their care within some way over a 24 hour period. Such a wide range of nurses participating in individual children's and young people's care appeared to impinge on effective care provision at times. Importantly, it appeared that this particular delivery of care severely inhibited the building of relationships between children and staff. For example, where children and young people were cared for by constantly changing members of the nursing team, it appeared that the opportunities open to nurses to learn the individual preferences, anxieties and wishes of those in their care were greatly reduced to the detriment of children and young people. This was summarised nicely by Louise (27):

> "I wouldn't be bothered about only having a few nurses looking after me. I don't have any nurses that I really like or hate. I suppose it would be nice to know the ones who were looking after you. I think that might be better because then they would know about you and what worries you and what you have to have done when. I think that more people in hospital would get better looked after if that's the way it was worked. There would probably be less people complaining about their treatment and all that. I think so anyway" (Louise, aged 16 years).

Other children and young people also expressed a preference for being cared for by a small group of nurses as Callum (6) explained:

> "You sort of see them [nurses] for 24 hours a day and so it'd be nice if you could get to know them better. Because it's so busy though you have a different nurse looking after you every day. I think that's a bit rubbish really. I mean the staff nurses. I know the assistants a bit more. I think that they have more time to chat to us and get to know us more. They are busy but the staff nurses are just that busy that they don't have enough time for talking to people and getting to know them" (Callum, aged 15 years).

The notion that being cared for by fewer staff would result in nurses getting to know children better was reflected also in the following account by Abby (1):

> "Being looked after by the same nurse is better as you get to know them and they get to know you" (Abby, aged 9 years).

Conversely however, other children commented that they preferred to be cared for by a large group of nurses for reasons related to personality, as Libby (26) explained:

> "I like to be looked after by everyone [all nurses on ward] rather than a small group of nurses in case there is someone I don't like" (Libby, aged 12 years).

Samuel (41) meanwhile, highlighted the constraints that existed within the ward resulting in nurses not always being able to spend time with children and young people and associated this negatively within the context of being cared for by different nurses:

> "I enjoy meeting new people so in some ways it's good to have lots of different nurses looking after me. It doesn't really matter who my nurse is anyway because they never come in to see you" (Samuel, aged 16 years).

The hospital within which the study was set had undergone radical change just prior to the research being undertaken. This resulted in wards being reconfigured leading to fewer nurses being available on bigger restructured wards. As a result many of the old wards were no longer in existence. The effects of these changes were recognised by many children and young people who knew the hospital prior to these changes being made and were reflected in their accounts around the provision of care. For example, several children and young people highlighted the impact of these changes upon both the nursing staff and themselves:

> "I know it's really hard for them [nurses]. They just don't have enough time. It's not really their fault. I think that's why the nurses end up leaving, they get fed up and leave. ... It's sad for us because we just might be getting to know them and then they're gone. Like on here, the staff just don't have any time. They're all too busy, especially the nurses. They're just stretched for time. ... These new wards are just too big. They're too big with not enough staff. It just ends up with the nurses being busy all the time. I think these wards are too big anyway. I think they're a big mistake" (Samuel, (41) aged 16 years).

Prior to the reconfiguration, many children and young people with chronic illnesses had been cared for on one medical ward which no longer existed. Talking about the "old ward" was central to the accounts of many young people and featured uppermost in their narratives. Predominantly these focused upon the relationships that existed between young people, nursing staff and fellow patients and the failure of these to continue into the new ward setting, as Samuel continued:

> "[Old ward] were much smaller. Everyone knew everyone didn't they? All the nurses knew the patients and the patients knew the nurses. It were like a big family. When you came in, you always knew most of the other patients who were in and you were friends together. I think we used to have much better relationships with the nurses before the wards changed round. Like we used to know each other and have fun with each other. That doesn't happen now. The nurses here are always having to rush. They just don't have the time" (Samuel, aged 16 years).

Charlotte (8) also reflected on the relationships existing in the wards prior to reconfiguration, contemplating on the effects the changes in restructuring had had, not only on the children and young people in terms of care provision, but also on the nursing staff:

> "It's like [old ward]. When we were all together on [old ward], we were like a big family really. Everyone knew each other right well. All the staff knew the kids, like the nurses and the children knew each other. Everyone were right close, weren't they? We were all in and out that much so everybody got to know each other. None of the other wards have ever been the same. It's just rubbish now. No one knows each other anymore. The staff hate it and that's why they leave and so it means there's always loads of new nurses. It makes it hard for us to get to know them and them to get to know us. It's rubbish" (Charlotte, aged 16 years).

The importance of these long term relationships with members of the nursing staff were clearly indispensable to young people as Callum (6) revealed when reflecting back upon his experiences prior to the reconfiguration:

> "We (young people with chronic illnesses) talk a lot about the staff. You know, how much we miss people when they leave. There's no nurses [from old ward] left around anymore. Everyone's gone and that's hard. People left gradually but for a long time there were at least a few "old" people around to see and talk to. They've all gone now, there's no one. We all miss having someone from the "old times". It was a blow when we realised that there was no one left" (Callum, aged 15 years).

Many young people recognised the constraints the recent changes within the ward setting placed upon nursing staff and the subsequent negative effects on the development of relationships. Dominic (10) explained that the ward was very busy and the way in which this impacted upon the care he received:

> "The nurses are rushed off their feet most of the time running around after everyone. They need about another one hundred nurses for there to be enough of them. ... You sometimes feel that no one is looking after you, as if you are just a number rather than a person" (Dominic, aged 13 years).

Similarly, Isabelle (20) also focused upon the constraints imposed by the ward re-configuration upon the nurses and subsequently upon herself:

> "The nurses don't have time any more to talk to us. Especially with me being in a cubicle. No one comes in to see me because they're all too busy. I only see someone when they come in to give me my IV's. I never see anyone the rest of the time. They just don't have enough time for us all. There's too many of us" (Isabelle, aged 14 years).

In this sub theme I have described children's and young people's experiences of care delivery. In the next sub theme I explore the ways in which children and young people valued nurses caring practices.

Value of nurses caring practices

Most of the children and young people were usually independent and self caring. However, for many the effects of their illness restricted their abilities to care for themselves whilst in hospital. These included instances where children were confined to bed or had limited mobility to access facilities within the ward, or simply where children felt too ill. Consequently, children and young people often described the care provided by parents and nurses as including those elements that children were unable to meet for themselves, such as washing and dressing.

Within their accounts, children and young people were invited to share their understanding of care. Clearly, many associated nurses and nursing as being synonymous with care and caring, using phrases such as "it is nurses who care for you. That is what they do", "the nurses job is to care for us all while we are poorly". For others, a connection was made between care and treatment with comments such as care "makes you better", "gets rid of being ill" and for one young person who had previously been diagnosed with leukaemia "puts you in remission".

Upon asking it became clear that children and young people valued the care provided by the nurses. For example, Yusuf (46) explained that:

> "I think that all the things the nurses do for us are really important. Like the way they care for us and look after us the best they can. It just would be impossible to be here without them" (Yusuf, aged 11 years).

Many children and young people believed that it was vital that nurses were able to care for them to get well. For example, Oliver, (35) aged 13 years, commented that "you feel safe when there's a good nurse looking after you, who knows what to do and how to look after you". The distinction between nurses' attributes and caring abilities were closely related in children's and young people's opinions but they found it difficult to unravel these as Louise (27) highlighted:

> "[Nurse] is nice and she looks after me really well, you know, takes good care of me. Well, perhaps it's because she's nice that she looks after me so well. I suppose because I can talk to her that helps a lot but because she's that sort of person who's nice to talk to then that means I like it that she looks after me. So, it's important to me that she looks after me really well, but at the same time it matters just as much that she's nice to me" (Louise, aged 16 years).

For Charlie (7) however, the importance of nurses caring for him well was related to severity of illness, as he commented:

> "I think it depends on what's wrong with you. If you're really ill then you need the nurses to be doing things for you but, most of the other time if you're OK or getting better, I don't think it matters so much" (Charlie, aged 11 years).

This sub theme has explored the value of nurses caring practices. Next I describe instances of "good" and "poor" care from the perspectives of children and young people.

Instances of "good" and "poor" care

Children and young people gave examples of times when they felt that they had received "good" nursing care, often relating this to "what a good nurse does for you". For instance, Oscar (37) related good care to an example when his nurse knew just how he liked to be cared for when he was feeling unwell. He explained that:

> "I had really bad stomach ache. It was so good that [nurse] was looking after me as she knows me now. She just remembered what to do from last time and just went on and did it. Got me the right pain killers and other tablets, got me a hot orange and pillow. I didn't have to tell her or anything. It was so good to feel that someone knew me well enough to know what to do" (Oscar, aged 11 years).

For Louise (27), reflecting back on previous hospital admissions when she had been very ill led her to recount instances where nurses had provided comfort by being "gentle with me and lifting me gently. Not being too rough but making me feel that they wouldn't drop me. They knew how to make the pillows be comfy and they always did. They never left you in a way that made you ache or hurt" (Louise, aged 16 years).

Conversely, children and young people reflected upon instances when they felt that they had received care that was poor. This was illustrated by Lydia (29) who associated poor care with having to wait for medications and a nurse being short with her. She described that "one of the nurses got cross with me because I needed a pain killer and she was too busy to get me one. And I was nearly crying because I had headache and then stomach ache" (Lydia, aged 10 years).

Joshua (23) meanwhile, remembered a time when he had been feeling unwell and a member of the nursing staff had wanted him to sit out of bed, recounting this as a negative experience:

> "I'd been feeling shocking and all I wanted to do was just lie down. And this nurse came and she was trying to force me to sit in a chair. I'd got the oxygen on and the monitor on and I felt that ill and she was grabbing hold of my legs trying to pull me out of bed. She was telling me that I was lazy wanting to stay in bed but it wasn't that. I did truly and honestly feel absolutely awful" (Joshua, aged 12 years).

In this sub theme children and young people have recounted instances of "good" and "poor" care. In the next theme I describe their experiences of medical staff.

Theme 2: Doctors: Curing

Children and young people with both acute and chronic illnesses spoke about medical staff within their accounts. As with the nurses, children and young people described the attributes of "good doctors" using descriptors such as "helped the most" and "nice". However, the attributes of "good doctors" were spoken of much less frequently than those of the nurses and tended to encompass those characteristics that related to children and young people recovering from illness, hence as curing rather than caring for them. In this sub-theme I explore children's and young people's perspectives of medical staff.

Children and young people appeared to associate medical care with "getting better" and symptoms subsiding as a result of treatment. As a result, this tended to be the yardstick by which children and young people judged a "good doctor". For Dominic (10), being admitted to hospital following a road traffic accident had resulted in a stay on intensive care and being severely ill initially. He commented that:

> "[Doctor] was just fantastic. He saved me I'm sure he did. I think I would have been dead if it had been any other doctor but him" (Dominic, aged 13 years).

Many children and young people who had been admitted due to acute illnesses described the doctor they met initially as being "the person who has done the most for me". Oliver (35), who was admitted due to an acute exacerbation of asthma resulting in him being extremely ill, described first arriving in Accident and Emergency:

> "I was panicking because I couldn't breathe. I was like gasping and crying and my chest felt really tight. It really hurt. [Doctor] was really good. She was dead calm and she got me on the nebuliser and on the drip and just kept telling me that I'd be OK. Because she was calm it calmed me down as well. After a bit I could breathe better and ... well, now I'm almost back to normal. She definitely made the most difference to me" (Oliver, aged 13 years).

For children and young people with chronic illnesses, relationships with medical staff developed over time and across the trajectory of the illness, as Charlotte (8) described when talking about her consultant:

> "Like [consultant], he's been my doctor since I was little so I know him right well. I get on OK with him. I suppose we're used to each other now and ... well, he knows me right well. Better than anyone else I suppose. Well, he's known me since I was two so he should do!" (Charlotte, aged 16 years).

However, Charlotte's account continued to describe some of the constraints that existed in relation to developing relationships with the medical staff. These included issues around continuity and familiarity due to the short rotations ascribed to more junior medical staff:

> "It's better with the consultants because at least you know them over a long time. Like the SHO's [senior house officers], well you see them everyday but you're just getting to know them when they leave. They're only here for about three months. It's not long enough. Even though you only see [consultant] twice a week when you're in, at least you get to know them over a longer time" (Charlotte, aged 16 years).

Difficulties such as these led to children and young people describing doctors as "not known as well as the nurses". This in turn constrained the development of relationships between children, young people and doctors. For other young people, a lack of explanation and discussion led to feelings of being insignificant. This was summarised by Callum (6):

> "I don't think the doctors have time to talk to us as individuals you know. They're just too busy. In clinic you're just in and out and that's it. They don't have the time to give us. [First consultant] is better though. He does always ask you how you're getting on. He's better than [second consultant]. He's just so matter of fact. It's right, you've been on this and now you have to go on that. I don't feel he ever talks to me. You know, talks to me as an individual. I don't feel like he knows me or wants to know me. I think that if the doctors could just give every person in clinic just five minutes to talk to us on an individual, sort of personal level, it would stop a lot of problems happening" (Callum, aged 15 years).

In this sub-theme I have described experiences of medical staff including children's and young people's perspectives of the attributes of "good doctors". In the next theme I outline children's and young people's experiences of being cared for by their parents whilst they were in hospital.

Theme 3: Being cared for by parents

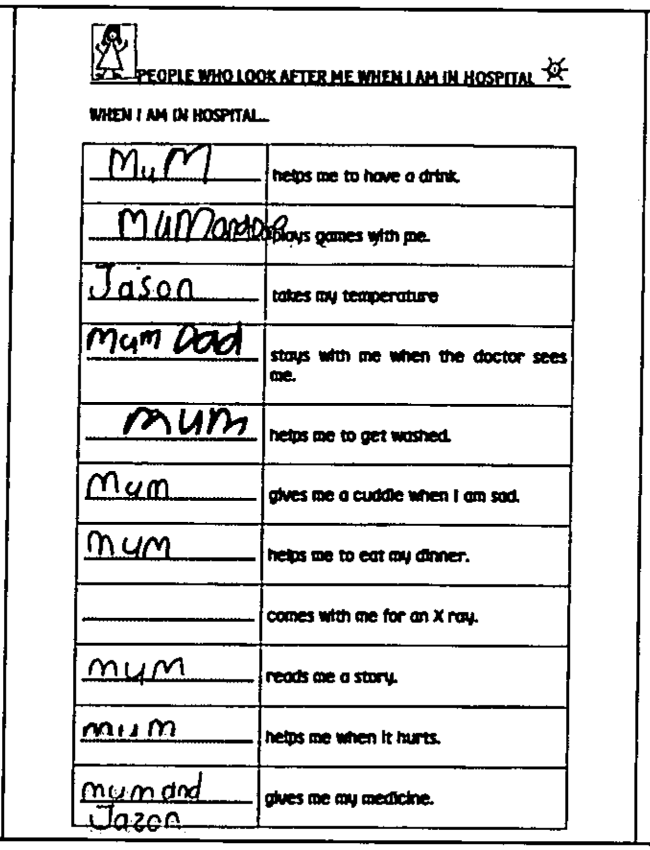
Introduction

The children and young people in the study spoke at length of their experiences of being cared for by their parents whilst they were in hospital. Their narratives included the elements of care undertaken by parents, their experiences of parents as carers within the hospital setting and their concern and anxieties over their parents' welfare. In this theme I explore these experiences from children's and young people's perspectives.

Role of parents

Children and young people described the role their parents played in their care whilst they were in hospital. These included the elements of care performed by parents and encompassed aspects such as "washing and dressing me", "giving me my medicines", "taking me to the toilet" and "takes me for my X ray". For example, Sarah, (42) aged 11 years, commented that "my mum helps me to get washed because I can't get my bandage wet". Many children and young people believed that their parents cared for them the most whilst they were in hospital. As Emily, (13) aged 12 years, commented, "my mum looks after me here really". This viewpoint was supported by Poppy, (39) (aged 6 years), "my mum looks after me. She does everything for me". For Harry (18), completing the "People who look after me in hospital" activity (see figure 8.4) was valuable in revealing that his parents, predominantly his mother, performed the majority of elements of his care. As Harry explained:

> "My mum helps me to have a drink and she helps me to eat as well. She plays games with me. We play Connect Four and hangman. My mum helps me to get washed and she reads me stories. My mum does everything really. But she's doesn't come with me for an X ray but I've never had one or I bet she would have" (Harry, aged 10 years).



PEOPLE WHO LOOK AFTER ME WHEN I AM IN HOSPITAL

WHEN I AM IN HOSPITAL...

MuM	helps me to have a drink.
MuMandad	plays games with me.
Jason	takes my temperature
Mum Dad	stays with me when the doctor sees me.
mum	helps me to get washed.
Mum	gives me a cuddle when I am sad.
mum	helps me to eat my dinner.
	comes with me for an X ray.
mum	reads me a story.
mum	helps me when it hurts.
mum and Jazon	gives me my medicine.

Figure 8.4 Activity by Harry

Children and young people described how their parents provided emotional support to them by "staying here with me", "keeping me safe from the needles", "talking and keeping me company", "playing games" and "making it seem more normal". For instance, James, (21) aged 12 years, explained that "my mum plays cards and dominoes with me to stop me getting bored, otherwise I might go stark raving loony". For others, parents' unique ability to provide a sense of normality in an unfamiliar situation was essential as Joseph (22) described:

> "My mum does all the usual things for me, just like she does at home. It just helps. It's like it feels as if it's not so odd when she's here. Like I'm not on a parallel planet" (Joseph, aged 10 years).

Children and young people with chronic illnesses, whose parents usually provided complex aspects of care and treatment within the home setting, often preferred for their parents to continue to provide this care within the hospital setting. This often entailed more complex elements such as physiotherapy or giving gastrostomy feeds. For example, Elijah (12), who has diabetes and was admitted to hospital with dehydration, commented that:

> "The nurses check my blood sugars. I usually do that myself. My dad gives me my insulin though and it's nicer for my dad to give it than the nurses" (Elijah, aged 8 years).

Similarly, Stephen (43), admitted due to an acute exacerbation of his eczema, commented that he preferred his mother to apply his creams and dressings:

> "I like it when my mum's here so she can put my creams on for me rather then anyone else have to do it. It's nicer for my mum to look after me than the nurses" (Stephen, aged 12 years).

In this sub theme children and young people have described the role their parents undertook in relation to their care. In the next sub theme I explore how children and young people experienced their parents as their carers whilst they were in hospital.

Experiences of parents as carers in hospital

Children and young people described their experiences of being cared for by their parents in hospital. For many children, this included expressing their feelings around their parents providing their care in an unfamiliar setting as Joshua (23) described:

> "It's not too bad or too strange my mum looking after me here, not as bad as I thought it would be. You know, not too weird considering you're in a place you don't know with your mum washing you from a washing up bowl and all that. I'd still rather be at home though" (Joshua, aged 12 years).

For other young people who were familiar with the hospital setting, their experiences focused more upon the elements of care that their parents were undertaking as Elena (11) explained:

> "It's like say my physio. I'm used to them [parents] doing it at home so I suppose it feels more funny when I'm here [in hospital] and the physio's doing it. Like my mum and dad know how I like it and I'm used to them doing it. Sometimes I don't like the physio's to do it because they can hurt a bit and not do it right. … I'm used to them [parents] doing it though for me here [in hospital] when the physio's too busy. Right from when I first came in [to hospital] when I was about one so I don't think about it much now" (Elena, aged 14 years).

Other young people drew attention to issues around the constant presence of their parents whilst they were in hospital. Whilst the input of parents was clearly valued, at times their continuous presence, particularly whilst being in a single room, could be restrictive for both parties. This was described by Isabelle (20):

> Isabelle: "In some ways it's been hard work being in here together. Like I love my mum to bits and I'm glad she's here but …"
> Isabelle's mum: "Because like now she's at this age, she's at that hormonal stage and stroppy stage and things, and like when we're at home and she gets into a strop she'll go upstairs, out of my way".
> Isabelle: "Out of her way so I don't get cheesed off even more".
> Isabelle's mum: "But now we've just been so close together for last week ..."
> Isabelle: "It's tough because you can't really get out of each other's way" (Isabelle, aged 14 years).

This sub theme has explored children's and young people's experiences of their parents as carers in the hospital setting. In the next sub theme I describe the importance of their parents' involvement from the perspectives of children and young people.

Importance of parents' involvement

The involvement of parents in their care whilst they were in hospital was clearly valued by children and young people. Many spoke about it being "nicer that my mum and dad do things for me", "it helps me get better more when my mum is with me" and "my mum makes me feel safe and it matters to me that she does things for me". For instance, on being asked if she liked the nurses doing things for her when she was in hospital Lydia (29) replied:

> "Sometimes. Sometimes though I really, really, really do miss my mum" (Lydia, aged 10 years).

Other children and young people associated the importance of their parents' participation in relation to the quality of care their parents were able to provide as part of their unique relationship with them. For example, Poppy (39) commented that "no one else in the whole world can look after me half as well as my mum does" (Poppy, aged 6 years). Saira (40) meanwhile reflected upon her mother's understanding of the way in which she liked to be cared for:

> "My mum just knows what to do for me and how to do it. She knows me better than anyone else and so she can do the right things for me. And she looks after me excellently well" (Saira, aged 9 years).

Many children and young people related the importance of their parents' involvement in light of the constraints imposed by poor nursing staff levels and "just not enough nurses to go round". For example, Hannah (17) commented:

> "I'm just so glad that my mum's here with me. If she wasn't I don't think there would have been anyone looking after me at all" (Hannah, aged 15 years).

Emily (13) voiced similar concerns around not being cared for if her mother was not present as "the nurses are nice but they don't come and see you and you're just on your own" (Emily, aged 12 years).

In this sub theme children and young people have described the importance of their parents' involvement in their care within the hospital setting. In the next sub theme I explore conflicts in care.

Conflicts in care

The children and young people in the study elicited instances where conflicts over care had arisen. This was illustrated by Dominic (10), in his teens, who described an account whereby his mother was expected to perform an element of care that he preferred her not to in relation to washing:

> "When I was in intensive care, the nurses had been washing me when I was really ill until this one day when this nurse suddenly shoved the bowl under my mum's nose and pulled the curtains round my bed. Well, I'm 13 and I don't want my mum to be washing me. Like my dad would have been bad enough but it would have been a bit better" (Dominic, aged 13 years).

Other children related similar experiences whereby nurses expected to perform aspects of care that children preferred their parents to undertake. For example, Saira (40) described the nurses' insistence on administering a daily injection that her mother usually gave at home. She commented that, "I don't want them [nurses] to do it because they hurt me. I'm used to my mum doing it and she doesn't hurt" (Saira, aged 9 years). Some young people identified these conflicts in relation to their lack of control over their parents' involvement in their care. This is illustrated in the following account by Anya (3):

> "If they're here my Mum and Dad end up doing my physio anyway. Like I don't choose for them to do it and they're just pushed into doing it. It would be nice to have a say in it though, definitely for me and for them too I suppose" (Anya, aged 15 years).

In the next sub theme I explore the concern children and young people had for their parents.

Concern for parents

Many children and young people expressed concern for their parents due to their continued presence with them in hospital. Many appeared to relate to the situation their parents were in and showed concern for their welfare, highlighting concerns over them being tired, missing meals, being worried and not being able to spend time at home. For Dominic (10), anxieties about his mother were paramount:

> "I get worried about my mum. It's like we've been here for a week and a half now and I don't think she's sleeping properly. She just looks that tired. She's not eating properly and I know she's worrying about me. I keep telling her to go home for a bit. Just to have a rest and all that. But she won't. She says she doesn't want to leave me but I'm OK now. She could go just for a bit" (Dominic, aged 13 years).

Similarly, Yasmeen (45) expressed concerns about her mother commenting that "I hope my mum's all right. Only I think she keeps crying because her eyes are all red and I know she misses my dad" (Yasmeen, aged 8 years).

As Anya's (3) earlier quote suggests, it appeared that parents, like children and young people, had little control over their involvement in the care of their children, with nursing staff largely determining this. Indeed, many young people drew attention to the high expectations placed on their parents by staff in relation to their care. This was illustrated by Isabelle (20):

> "My mum has to do everything for me. It's just sort of expected that she does it all. I'd rather that she does it but nobody ever says for her to have a bit of a break or fetches her a drink or anything" (Isabelle, aged 14 years).

Florence (14) similarly highlighted the lack of consultation between children, young people, parents and nursing staff in determining involvement in care:

> "They [nurses] never ask or find out if your mum or dad want to look after you. It seems to sort of be decided that they will by somebody high up. I think they [parents] have to look after you whether they want to or not" (Florence, aged 10 years).

Louise (27) meanwhile highlighted the pressures facing her own mother and other parents whilst their children were in hospital:

> "I feel so sorry for my mum. She always comes and stays in hospital with me and it must be awful for her. She never gets chance to have a proper meal or to sit down properly with a cup of coffee. And nobody can sleep on those stupid pull down bed things they have. And she's tired already because she's been looking after my granddad because he's not been well either. No one ever comes round to see if the mums are OK. It's all just taken for granted that they are but I think some of them are that knackered and must feel that down that they must be close to cracking up" (Louise, aged 16 years).

This theme has explored children's and young people's experiences of being cared for by their parents within the hospital setting. In the next theme I describe their experiences of caring for oneself.

Theme 4: Caring for oneself

Introduction

Within their accounts, children and young people described their experiences of actively participating in their own care whilst they were in hospital. This included the elements of care undertaken, the ways in which children and young people co-ordinated their own care on occasions and those factors which hampered or restricted their own caring abilities.

In this theme I explore these experiences from the perspectives of both acutely and chronically ill children and young people.

Children's and young people's role in care

Many children and young people described playing an active role in their care. This included attending to hygiene needs such as washing, dressing and toileting where possible and other aspects of care including taking medications and reporting any new symptoms or bodily changes in order to initiate medication or treatment. For example, Georgina (15) explained how she reported her headaches increasing in intensity to nursing staff in order to receive appropriate medication and initiate examination by medical staff:

> "When my head starts to ache I have to tell one of the nurses so that by the time it gets really bad the doctor is here and I can have some medicine" (Georgina, aged 5 years).

Georgina's quote reveals her understanding of how to alert assistance alongside her awareness of the implications of time. Similarly, Joseph, (22) aged 10 years, described his experiences of reporting worsening symptoms around his asthma, including chest tightness and feeling wheezy to staff, "when my chest starts to hurt and it gets harder to breathe I tell someone so I can get a nebuliser".

Children and young people with chronic illnesses often undertook elements of care that were more complex due to their existing experience in providing these aspects of care. These included administering intravenous antibiotics to themselves in the nurses' presence, the application of creams and helping with dressing changes. For example, Charlotte (8) described administering one antibiotic when the nurse was present, "I gave the [name of antibiotic] myself. It's only a push and I can give it slower than the nurses because sometimes they push it too fast and it stings" (Charlotte, aged 16 years).

Whilst many chronically ill children and young people had long standing experience of providing certain elements of care within the home setting, some children developed experience in relation to certain elements of care received in the context of the hospital, due to their long standing need for treatment. For example, Sarah (42) who was frequently admitted to hospital due to having an ulcerated leg had developed extensive experience around having her leg dressings changed and participated in these alongside nursing staff:

> "I help the nurses do them [dressing changes]. I keep their packet like sterile by not touching it and sometimes I wash my hands first and pick the dry skin off with those tweezer, forcepy things. If it's a nurse who's not used to doing my leg I tell them what to do. You know, how's best to do it and if they're not doing it properly I'll tell them" (Sarah, aged 11years).

Feeling ill, being disempowered in the unfamiliar hospital setting or even feelings that varied on a day to day basis could all affect children and young people's abilities to care for themselves. For example, Leila (25) reflected on feeling unwell and not wishing to walk down to the bathroom for a wash. She commented that:

> "I felt rough because I'd not slept with having bad stomach ache. Anyway they [nurses] were trying to make me go down to the bathroom to get washed and I just wanted to lie on my bed and not really have a wash at all, or just get my mum to do it for me. My stomach hurt and my head ached and I just felt that that day I did not want to get washed by myself' (Leila, aged 10 years).

On other occasions, children and young people simply did not wish to participate in care and enjoyed receiving care and attention from others as Abby (1) explained:

> "Yesterday morning my mum helped me to get bathed. It was just nice to have her to myself for a bit and to soak in the bath and not think about having to do anything" (Abby, aged 9 years).

Similarly, whilst many children and young people with chronic conditions who were used to carrying out elements of their care at home were keen to be involved in these elements of care within the hospital setting, others found that the ward provided the opportunity to relinquish demanding care regimes to staff. This was clearly a relief to Callum (6):

> "I've been quite ill recently and because of that and having to have more and more treatment at home, I just feel absolutely shattered. In some ways it's a relief to be here. You know, just to be able to share some of my everyday treatment with someone else. Like, to let the nurses do my IV's while I just lay and watch telly" (Callum, aged 15 years).

However, on occasions young people described having to care for themselves due to the ward being busy and nursing staff being unavailable to assist them as Charlotte (8) eloquently described:

> "It's just that sometimes you feel like you'd like a rest from it all and for someone else to take over but trouble is, there's no one there to do it. Loads of times the nurses are too busy to help you or to do it for you and so ... It's like you might as well do it yourself really, no matter how bad you feel" (Charlotte, aged 16 years).

This sub theme has described the roles undertaken by children and young people in relation to their care. In the next sub theme I describe how some children and young people believed that they co-ordinated their own care.

Co-ordinating care

Some children and young people suggested that the constraints imposed upon the nurses through low staffing levels and bigger wards resulted in children and young people feeling responsible for ensuring that they received the correct care and treatment on time, or in other words, co-ordinating their own care. Undertaking this co-ordination of care did not appear to be sought by any of the children or young people but instead seemed to be imposed upon them due to the aforementioned constraints. As a result, many children and young people appeared to feel frustrated and resentful about this responsibility. As previously discussed in Chapters 6 and 7, many chronically ill children and young people described instances when they needed to "chase the nurses" for their medications, that is, ask for them when they were late or forgotten. For example, Oscar, (37) aged 11 years, recounted an instance when he had to remind nurses that his pre-medication was 20 minutes late prior to him undergoing surgery. He commented that:

> "I think I'd have ended up going to theatre without it if I'd not told the nurse. It was obvious that she didn't even know that I should have had it. I hate going to theatre anyway. It scares me to death and then to have to run about telling people that I should be having some medicine to calm me down is just a joke" (Oscar, aged 11 years).

Lydia (29) similarly illustrated an example where she had been forced to "hassle" the nurses to bring her some pain relief when the ward was particularly busy:

> "And I know they're [nurses] busy but I kept asking and asking for something for my head ache and they kept saying they would get it for me but they never did. Like two hours had gone and I'd been hassling them and I went out again and it turned out that the nurse had forgotten about it" (Lydia, aged 10 years).

Feeling responsible led to children and young people being observant of care and procedures undertaken by nurses in order to ensure that these were performed satisfactorily as Sarah's (42) "if they're not doing it properly I'll tell them" revealed. For others however, the burden of responsibility around care led to resentment when having to remind the nurses about medications and procedures as often this could lead to bad feeling and conflict. This resulted in a "double bind" whereby children felt that they wanted to trust and develop relationships with staff but instead had to "chase" or "hassle" them regarding their care. This was explained by Elena (11):

> "You do feel bad when you have to keep telling the nurses that you should have had this medicine or that tablet or whatever. It's like you know they're busy but on the other hand they should know when your stuff's due. But still, you feel like you want to be nice to them so they'll like you and be nice back. You don't want them to think you're a nuisance" (Elena, aged 14 years).

This theme has described children's and young people's experiences of caring for oneself. In the next theme I explore expertise in care.

Theme 5: Experts in care: Children, parents and nurses

Many children and young people with chronic illnesses described both themselves and their parents as being expert in their illness and its daily management. Within their accounts they included the often complex elements of care they and their parents undertook on a regular basis and the attributes they believed were essential to their expertise. However, many believed that their status of being expert was not always acknowledged by nursing and medical staff. In this theme I explore these experiences of expertise from the perspectives of both acutely and chronically ill children and young people.

As a result of their long term illness experience, children and young people with chronic illnesses were competent in the management and execution of their illness management and its daily treatment. Indeed, this group of children and young people viewed themselves as the experts in their illness and its on-going care. Children and young people possessed an knowledge of their condition. They identified their responses to their illness and treatment, including their recognition of any early symptoms or pain and warning signs of impending problems as being an essential part of their expertise. Furthermore, they were often highly knowledgeable about their own particular disease process, holding embodied knowledge. This was illustrated by Hannah (17):

> "I don't think that anyone knows as much about my CF and how best to manage it than me. After all I live with it every day. I know when I'm going to start being ill with my chest, when I start getting pain or getting breathless. Sometimes I know the best thing they should start me on, like which antibiotic. I just know which ones I respond to best and which ones will help me when I start with a bad chest and it's not always the same antibiotic. I sometimes need different ones depending on what sort of bad chest problem I've got" (Hannah, aged 15 years).

Children and young people perceived their parents as being experts also. They recognised that they too held knowledge regarding their treatment and illness and importantly, understood their own unique preferences for certain aspects of care. For instance, Elijah (12) explained that:

> "My mum and dad know all about my diabetes and what to do. Like I do my blood sugars, or they do sometimes, and they know about working out how much insulin to give me and how much food. They know how to do my insulin like I like it so it doesn't hurt. They're ace" (Elijah, aged 8 years).

Many children and young people, and their parents, were adept at carrying out complex aspects of care, including administering intravenous medications, injections, monitoring vital signs, administering oxygen therapy and performing suctioning and physiotherapy. Subsequently, this group held a formal knowledge from the training they had received prior to undertaking this complex care and an extensive, experience of executing it on an almost daily basis. As a result, many children and young people were aware of the most effective way to carry out certain procedures and both possessed and used their knowledge to assess and judge the professionals' level of expertise as Emily (13) exemplifies:

> "The other day one of the nurses was setting up my feed and she was doing it all wrong. She didn't run the feed through the machine, she was just letting it run through the set, so I had to tell her about that. And then she was trying to put the set in the pump all wrong so I had to show her how to do that. And then you'll never guess what. She was just going to start running it without checking the ph in my stomach on the litmus paper. I told her that if the tube [naso gastric tube] was in my lung she'd get the sack. I think she needs to go back to nurses' school as it is" (Emily, aged 12 years).

The daily performance of what was often complex technological care led to children and young people having an experiential and intuitive knowledge of what was "not normal". Consequently, many children and young people described being able to identify potential problems earlier than staff. At times this was used as a basis for challenging professional viewpoints as Isaac (19) commented:

> "I just knew that my Crohns was flaring up again. My stomach started nagging and I was feeling not sick, but just queasy. My doctor at home told me I'd got a virus but I knew he was wrong, so I told him. Sometimes I just know that it's starting up again but can't put my finger on just why I know exactly. Anyway, surprise, surprise, he was wrong and I was right yet again and here I am in hospital" (Isaac, aged 13 years).

Having this knowledge and expertise around their illness and its management led some young people and their parents to believe that they had little need for input from the nursing staff. Isabelle (20) and her mother illustrated this belief as they described a typical morning in hospital:

> Isabelle: "She [nurse] comes and tells us".
> Isabelle's mum: "She comes and says I'm your nurse today".
> Isabelle: "OK. I won't need you but OK!" (Laughs).
> Isabelle's mum: "Well, I do all the treatment here anyway. I do all the physio and everything. They don't do anything. We do it all ourselves" (Isabelle, aged 14 years).

Despite this long standing experience and expertise however, many children and young people expressed their feelings that their knowledge and understanding was disregarded at times by both nursing and medical staff as Charlotte (8) revealed:

> "It's like for me, and everyone else on this ward with CF, we might know everything there is to know about CF. Well, we do and we know how to do all our treatment 24 hours a day, seven days a week and what's more we don't just know it, we do it. But ... I don't think that people like the nurses and say [consultant] treat us like we know as much as we do. They still think that they know better than us because they've got a medical degree or a diploma in being a nurse or whatever. It's like because we're only teenagers and not nurses or doctors, we don't really know anything" (Charlotte, aged 16 years).

The children and young people in the study described many positive elements around being cared for within the hospital setting. However, despite these, many also shared less positive examples around their experiences of care. These included examples of care perceived as being poor and issues around low nursing staff levels and busy wards impacting negatively upon the development of relationships with staff and care delivery as a whole. In turn, on occasion this led to conflicts in care with children and young people believing that their own or their parents involvement was essential if care and treatment was to be received. Consequently, many demonstrated concern for their parents due to the high expectations placed upon them. Meanwhile, many children and young people with extensive expertise in their illness and its management felt that their knowledge and experience was disregarded by staff.

It appeared that these negative elements resulted in children and young people losing independence and control. As described in Chapter 6, a loss of control subsequently led to feeling powerless. Conflicts around care and the expectations enforced upon children, young people and their parents led to feelings of disruption and uncertainty around the provision of care.

In the next recurring theme of restoring equilibrium I describe the strategies undertaken by children and young people in order to manage the disruption, powerlessness and uncertainty being cared for in hospital incurred.

Theme 6: Restoring equilibrium

As described, children and young people experienced disruption, powerlessness and uncertainty whilst they were in hospital in relation to the provision of care. However, many utilised a range of actions including harnessing ways of thinking positively about their care experiences in order to redress the imbalance of power and disruption and subsequently restore equilibrium. As outlined with regard to children's and young people's experiences of being in hospital and being ill and undergoing treatment (described in Chapters 6 and 7) it appeared that restoring equilibrium diminished the disruption and powerlessness experienced.

It appeared that for many children and young people in the study restoring equilibrium around their care experiences could be achieved by identifying the positive instances that had occurred and reflecting on these at times when experiences were less affirming. These encompassed positive incidences of nursing care, particularly when children and young people believed they had been able to influence circumstances for the better. For example, Malachi (31) spoke about a time when he had been able to affect his mother undertaking a more active role in his care. He explained that:

> "I hate having to take those tablets that dissolve, that pink one. The nurses bring it down but they want you to just swig it down because they're in a hurry and it just makes me gag and either feel sick or actually be sick. My mum can sit with me and help me to take it a little bit at a time but the nurses always say that they can't let my mum give it. Anyway, yesterday there was a nice nurse and I pleaded and pleaded with her and she gave in! She left it with my mum to give me. It was a lot better that way. I didn't feel sick at all after it" (Malachi, aged 13 years).

Instances such as these often resulted in positive relationships being formed between nursing staff and children or young people. These were clearly important to them and were often recollected. For example, Violet (44) reflected upon a relationship that had developed with one of the nurses during a previous admission to hospital remembering that, "[nurse] was so lovely to me. I absolutely loved it when she looked after me. She was my most favourite nurse ever and I always remember how she was nice to me when I get headache" (Violet, aged 9 years). Similarly, Katie (24) commented that "it helps so much that the nurses are nice and kind to you. It can make it seem a lot better when they are sort of like your friend" (Katie, aged 7 years).

Even where children and young people recounted times where they felt care had been poor, many recognised and acknowledged the constraints that existed upon staff and used these as a reason to negate these instances. For example, many highlighted the low nursing staff levels and the large busy wards in an attempt to counterbalance reasons why medications might be late or treatment waited for. In some instances, young people gave examples of poor care but then countered these with defending the nurses, drawing attention to the difficult situation they were in, as illustrated by Callum (6):

> "It's like you have to wait for ages for your medicines and you still don't get them so then you have to remind the nurses that you should have had them about two hours ago. That's a pain but ... well, it's not really their fault. Like they're just so busy and they don't have enough time for everybody. They're doing the best they can and I think they feel as fed up with it as we all do" (Callum, aged 15 years).

Many children and young people recognised the essential care and support they had received from their parents whilst they had been in hospital. Benito (5) described the way in which his mum had stayed with him throughout his stay in hospital and the way in which this had positively affected his admission:

> "My mum's been with me all the time. She's even slept with me at the side of my bed. It's much nicer to have my mum here with me. I might have been too scared to have stayed here by myself" (Benito, aged 6 years).

For others, the care their parents had provided for them had been indispensable. For example, Louise (27) aged 16 years, recounted the unique and vital care her mother had provided for her both during this admission and at other previous times when she had been receiving treatment for leukaemia:

> "It just makes all the difference my mum being with me. You know, being able to fetch me things, holding my hand when I feel sick, putting a damp flannel on my head when I had headache with the chemotherapy. All the things that the nurses can't do because they're too busy. And even if they weren't too busy and could do them, they still wouldn't know how to do things like my mum does. My mum just knows me so well she does things even before I ask" (Louise, aged 16 years).

Many children and young people also recognised another positive benefit of having their parents' present and enjoyed the undivided attention they were receiving. This was illustrated by Maija (30):

> "I just love having my mum here with me. I've got her all to myself. At home I have to share her with [siblings] but here she's only got me to concentrate on so she's all mine" (Maija, aged 9 years).

Other children meanwhile described their delight around "getting presents" and "being spoilt" by their family, as Florence (14) explained:

> "I've had sweets and comics and loads of other presents. I don't usually get this spoilt on my birthday or at Christmas" (Florence, aged 10 years).

For those children and young people with chronic illnesses and extensive experience in their illness and its management, reflecting on instances when their expertise had been both recognised and acknowledged was a positive element. This was illustrated as I began to interview Samuel (41). As we began talking, a staff nurse came in to the cubicle to ask Samuel about his allergies and sensitivities to antibiotics as there seemed to be some confusion with the doctors wanting to prescribe medications that the staff nurse thought he was allergic to. Samuel contemplated later in the interview on his pleasure that the nurse had both accepted and acknowledged his awareness of his allergies.

This group of young people highlighted also examples whereby not only their own expertise had been noted but that of their parents. This was demonstrated by Hannah (17):

> "[The clinical nurse specialist] said to my mum, do you want me to write you a reference because you've been Hannah's full-time mum, you've been a nurse and you've been a tutor, teaching other people what to do. You've done everything you could do for her and more. Don't you think that's good? She'll get any job going by the time she's finished!" (Hannah, aged 15 years).

Despite children and young people with chronic illnesses recollecting instances whereby they felt that care had been negative, the respite that being in hospital offered for both themselves and their parents was a positive element that was both valued and recognised, as Elena (11) described:

> "It's nice to have a bit of a break from it all. You know, you get a bit sick of having to think about medicines and physio all the time. It just gives you a break away from it. You can let someone else think about it for you instead. Like while I'm here the physio's do most of my chest physio and that's good because it gives my mum a break as well" (Elena, aged 14 years).

Children and young people experienced disruption, powerlessness and uncertainty in relation to the provision of care whilst they were in hospital. However, it appeared that undertaking a range of strategies enabled them to redress the imbalance of disruption and powerlessness and restore equilibrium. In turn this diminished the disruption and powerlessness experienced and reduced feelings of uncertainty.

Summary

In this chapter I have explored children's and young people's experiences around care within the hospital setting, presenting these within six themes; being cared for by nurses, doctors: curing, being cared for by parents, caring for oneself, experts in care: children, parents and nurses and restoring equilibrium. Whilst previous work has related to experiences of children's nursing within specific settings such as mental health settings, the community or ward, this study provides both insight and new knowledge into children's and young people's experiences within the wider setting of the hospital.

Children and young people described their experiences of being cared for by nurses, doctors, parents and caring for themselves whilst in hospital. Many children and young people with chronic illnesses believed themselves and their parents to be the experts in their illness and its daily management. However, many of them believed that this expertise was often discounted. Whilst children and young people described many positive elements around being cared for within the hospital setting, many also illustrated negative examples around their experiences. These less positive experiences led to feelings of disruption, uncertainty and a loss of independence and control, resulting in feelings of powerlessness. However, children and young people harnessed a range of strategies (see pages 218-219) in order to redress the imbalance in power and disruption and restore equilibrium.

Whilst it may be expected that children and young people would experience disruption and powerlessness whilst receiving care in hospital, the active strategies and social agency undertaken in order to mediate the ensuing effects provide original insight into children's and young people's experiences of care in hospital, not previously identified within this setting. Furthermore, by engaging with the diverse group of children and young people brought together through admission onto a general children's ward, this study reflects the real world that children and young people who are ill find themselves in, whereby those with extensive experience of being in hospital are cared for alongside those with only minimal hospital experience. By providing equity in terms of children's and young people's engagement and participation, this adds to the existing body of knowledge through its exploration of the experiences of the diverse group of children and young people as a whole, regardless of age, illness or hospital experience.

The ways in which the children and young people with diverse experiences harness active strategies and exert their own social agency in relation to the care they receive has strong resonance with and links to similar findings presented in the previous two findings chapters. I take the core resonances of disruption, uncertainty, powerlessness and restoring equilibrium and locate these theoretically within the next chapter.

CHAPTER 9:

DISRUPTION, UNCERTAINTY, POWERLESSNESS AND RESTORING EQUILIBRIUM

CHAPTER 9: DISRUPTION, UNCERTAINTY, POWERLESSNESS AND RESTORING EQUILIBRIUM

Introduction

In Chapters 6 to 8 I explored children's and young people's experiences of hospital in terms of being in the hospital setting itself, being ill and undergoing treatment and experiences of care and caring. As I came to know the data it was clear that I needed to draw the themes together to create a more meaningful understanding of children's and young people's experiences. I looked at the meanings that were apparent across and within the themes and, as I have started to outline in the previous chapters, four feelings appeared to resonate across all of the children's and young people's stories, drawings and my other data. As I started to look at these four feelings I saw how they related to each other, influenced each other and helped explain the children's responses and experiences. It became clear that disruption was a core experience for the children and young people and that the disruption of their lives was linked to feelings of powerlessness and uncertainty. However, it was also clear that the children and young people responded to this sense of disruption and tried to overcome their feelings of uncertainty and powerlessness by aiming to regain a sense of control. Seen in the context of disruption, powerlessness and uncertainty, I framed their attempts to regain control as their attempt to restore equilibrium. Figure 9.1 shows how disruption is composed of powerlessness and uncertainty and that restoring equilibrium draws on different strategies and positivity.

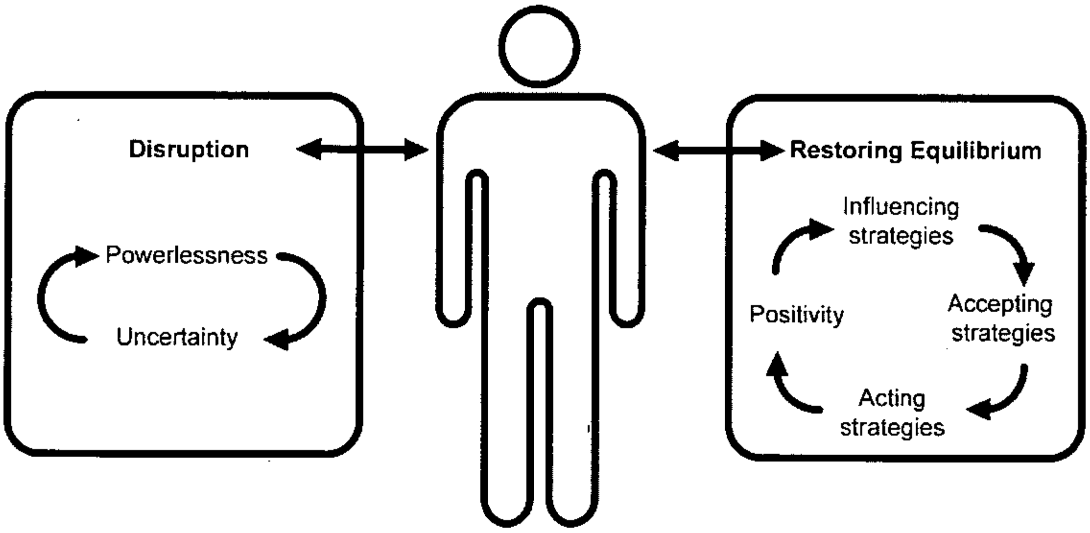


Figure 9.1 Components of disruption and restoring equilibrium

Children's and young people's accounts revealed that disruption was experienced as a result of a complex variety of factors, situations and people impacting upon their experiences of being in hospital. In the first part of this chapter I discuss children's and young people's experiences of disruption alongside their feelings of uncertainty and powerlessness in relation to being in the hospital setting itself, being ill and undergoing treatment and experiences of care and caring. Importantly I make comparisons with, and add to, the existing theory around disruption. The second part of the chapter is a discussion of the strategies (influencing, accepting, acting and positivity) which were undertaken by children and young people in order to restore equilibrium. Lastly, I link these to and extend existing theory.

Locating disruption, uncertainty and powerlessness

This study explores children's and young people's own experiences of disruption in the ward setting, adding to the existing body of knowledge (such as that by Hall and Stacey (1979) which noted how hospitalisation disrupts people's social worlds) by describing those specific elements that led to disruption, uncertainty and powerlessness. Disruption occurred as a result of being in the hospital setting itself due to both the loss of normal daily routines and activities and separation from family and friends. The unknown and different nature of the ward and hospital setting further added to the disruption and brought about feelings of uncertainty. This, alongside uncertainties regarding the social order of the ward, due to ambiguity around staff expectations and a lack of information, heightened existing fears and anxieties. The routine of the ward was experienced as being inflexible to the requirements of individual children and young people. As such, children and young people expressed concerns that they had to "fit into" the ward routine. As a result, the inflexibility and uncertainty of the ward social order negated against children's and young people's usual everyday routines and activities leading to further feelings of uncertainty and powerlessness.

The restraints and invasions imposed by both illness and treatment led to children and young people experiencing both disruption and powerlessness whilst they were in hospital, resonating with work by Benner and Wrubel (1989) and Kleinman (1988) revealing the disruption caused by illness in adult's social worlds. The disruption the children and young people experienced was further exacerbated by negative care experiences. This in turn eroded their independence and added to their uncertainty in situations and emphasised their sense of being powerless and lacking control.

My search to make sense of the emergent concept of disruption within my findings led me to Williams' (2000) work in relation to Bury's (1982) conceptualisation of chronic illness as a "major kind of disruptive experience" (2000: 43). Bury suggests that the experience of illness, particularly chronic illness, profoundly disrupts the structures of everyday life, its taken-for-granted features and the tacit stocks of knowledge upon which they rest. Williams singles out three aspects of this disruption. Firstly, that of "taken for granted assumptions and behaviours" (2000: 43), resonating once again with children's and young people's narratives of normality prior to entering hospital. The second of these is those disruptions in the explanatory frameworks necessitating a re-thinking of an individual's biography. In relation to this Williams describes key questions such as "why me" and "why now". Whilst many children and young people in my study demonstrated similar questioning, many also demonstrated responses such as "you've got to get on with it" suggesting a degree of pragmatism in terms of an acceptance and positive response to the disruption of illness. Thirdly, Williams highlights a practical response to disruption involving the "mobilisation of resources" (2000: 43) thus acknowledging the meaning of disruption for those experiencing it, alongside the setting in which it occurs, and the resources necessary to respond to it. Whilst Williams' work addresses adults' experiences of, and responses to, disruption, it relates to my study as it enabled me to (i) explore the meaning of disruption from the viewpoint of children and young people, (ii) examine the ways in which the ward and hospital settings affected experiences of disruption and (iii) explore the ways in which children and young people respond to disruption by attempting to restore equilibrium. Thus, Williams' work with adults alongside my study reveals differences and similarities between the responses of adults and children/young people to disruption. Whilst my findings demonstrate that children and young people across the whole age range have similar responses to disruption, they draw upon parents and other close family members to help mediate this whereas adults may draw upon spouses and other close family members in order to affect a similar response.

The literature around disruption is predominantly adult based although this concept has been mentioned within the literature around children's nursing. For example, previous work has explored children's nurses' experiences of the disruption engendered by parents' participation on children's wards, describing the effects of this disruption on the socialisation process and the ways in which nurses undertook a range of strategies in order to manage parents (Coyne 2007). This is of significance as the setting corresponds to the study setting and describes direct actions undertaken by nurses in managing the ensuing effects of disruption. However, Coyne's exploration of disruption is taken from a professional stance whilst my work describes disruption from the perspectives of children and young people themselves.

Of direct relevance to my study is the work of Levealahti, Tishelman and Ohlen (2007) who described the narratives of participants with lung cancer from disruption caused by their illness and treatment to eventual reintegration into continuing normal life. Levealahti, Tishelman and Ohlen depict their adult participants' journey from "normal life" through the trajectory of their sickness experience. This resonates with children's and young peoples' accounts of their "normal lives" prior to their journey through the hospital experience with its ensuing disruption. Whilst Levealahti, Tishelman and Ohlen's study focuses on adult journeys my study presents an addition to the literature in that it reveals the extent to which children and young people experience similar levels of disruption whilst in hospital and undergoing treatment.

I next move on to locate restoring equilibrium.

Restoring equilibrium

In an endeavour to counterbalance the effects of disruption, powerlessness and uncertainty experienced within the hospital setting, children and young people undertook a range of strategies in order to attempt to restore equilibrium. The concept "restoring equilibrium" is not widely referred to in the nursing literature in terms of experiences of care, although papers have identified maintaining equilibrium in terms of making informed choices during pregnancy (Levy 1999) and as a theory of job satisfaction for community mental health nurses (Wilson and Crowe 2008).

Whilst only limited work uses the terms "maintaining" or "restoring equilibrium", many studies refer to "balancing" as a core concept within their findings (see for example, Twinn's (2006) notion of balancing uncertainty and acceptance in Chinese women's responses to an abnormal cervical smear result, Giske and Artinian's (2008) definition of gastroenterology patients' experiences of the diagnostic phase as "balancing between hope and despair" and Thulesius, Hakansson and Petersson (2003) account of balancing as a basic process in end-of-life cancer patients). However, these studies appear to refer to balancing as a fluctuating process moving between two or more states, (uncertainty and acceptance in Twinn's work and hope and despair in Giske and Artinian's study) whereas the concept of restoring equilibrium for the children and young people within the hospital setting appeared to be a relatively stable state once achieved.

Importantly however, Faye and Irurita's (2003) study of the social and psychological experience of having hepatitis C describing participants as moving through the basic social psychological process of "balancing perspective", defines balancing as maintaining a state of equilibrium with regard to living with the hepatitis C virus (HCV). Faye and Irurita further elaborate on this state of equilibrium as one which "established and consolidated a balanced life perspective that incorporated the component of HCV" (2003: 92). This relates to the children and young people within my study for whom restoring equilibrium established a perspective that incorporated the disruption, uncertainty and powerlessness of being in hospital, being ill and undergoing treatment and experiences of care.

It would appear that resilience is a fundamental element of children's and young people's abilities to restore equilibrium. Indeed, longitudinal studies on children born into adverse situations form much of the current understanding of resiliency (DuPlessis Van Breda 2001). Resilience has been defined as "the self-righting tendencies of a person, both the capacity to be bent without breaking and the capacity, once bent, to spring back" (DuPlessis Van Breda 2001: 5). This echoes the experiences of children and young people in "bouncing back" from the adverse effects of being in hospital.

Earvolino-Ramirez (2007) identifies adversity as being the main antecedent to resilience. She argues that challenge, change and disruption are aspects of adversity that are present before the process of resilience can occur. Indeed, it has been argued that it is the disruption that allows resilient qualities to be learnt or tapped into in order to achieve resilient reintegration. Undertaking actions such as these correlates with literature examining resilience in children and the ways in which children and young people positively adapt to and survive within adverse conditions (DuPlessis Van Breda 2001). The notion of restoring equilibrium as it is applied to my study depicts children's and young people's experiences of mitigating the effects of disruption, powerlessness and uncertainty, demonstrating children's and young people's agency. Importantly, the actions undertaken by those who participated in this study adds further depth to the challenges to traditional Western conceptualisations of children and young people as powerless, incompetent, passive and dependent and instead identifies them as active participants in shaping their hospital experiences.

A range of strategies and actions were utilized by children and young people in order to restore equilibrium and thus redress the imbalance caused as a result of disruption and its associated uncertainty and powerlessness. These actions and strategies were internal to children and young people themselves and demonstrated their own abilities in restoring equilibrium. Children and young people drew also upon external factors, including parents, nurses, family and friends, in an attempt to restore equilibrium. In this section I outline those actions and strategies undertaken in terms of "influencing", "accepting", "acting" and "positivity". I will explore these in more detail in the final chapter.

"Influencing" strategies

Children and young people described many instances whereby they had influenced circumstances and changed them positively, in turn limiting the effects of disruption, uncertainty and powerlessness. These included for example, both promoting and influencing the presence of family and friends in order to minimise feelings of disruption and powerlessness. Efforts to influence the maintenance of individual routines also reduced feelings of loneliness and isolation thus lessening experiences of uncertainty.

"Accepting" strategies

Many children and young people outlined acceptance strategies in order to regain some control over circumstances they found themselves in and thus reduce feelings of disruption, powerlessness and uncertainty. For example, these included accepting the need to be in hospital, and that it was the "best place" for them in order "to get better" or "get back to normal", accepting the more negative aspects of being in the ward including "getting used to" and "going along with", acceptance of being ill and undertaking interventions in order to feel better and acceptance of the disruption of treatment in order to return to health.

"Acting" strategies

Children and young people described using many "acting" strategies in an attempt to lessen the disruption, uncertainty and powerlessness associated with being ill and in hospital. These included dealing with pain by being stoical or self sufficient through anticipating pain and undertaking comfort measures, drawing comparisons with others more poorly than themselves, complying with treatment and viewing it as something that needed to be "got through" so you need to "just get on with it" and gaining the necessary knowledge and information in order to understand and actively participate in illness management. Gaining information about their illness and treatment enabled children and young people to feel more involved and subsequently in control. In turn this appeared to reduce their fears and anxieties regarding being ill. At times, gaining information provided children and young people with the opportunity to make choices and decisions regarding their treatment thus providing important opportunities for reducing feelings of powerlessness.

"Positivity"

Harnessing ways of thinking positively about the circumstances in which they found themselves aided many children and young people in redressing the imbalance of powerlessness, uncertainty and disruption and subsequently regaining a degree of control. These included thinking positively about being in hospital itself by "acquiring optimism in the face of adversity" and identifying positive instances during their time in hospital and reflecting upon these. These included positive incidences around care, occasions when children and young people had been able to influence circumstances positively, times when their own illness expertise had been recognised and acknowledged and supportive relationships with hospital staff.

Summary

In this chapter I have discussed children's and young people's experiences of disruption, alongside feelings of uncertainty and powerlessness, in relation to being in the hospital setting itself, being ill and undergoing treatment and experiences of care and caring, drawing upon and adding to the existing theory around disruption. I have followed this with a discussion of the strategies undertaken by children and young people in order to restore equilibrium alongside existing theory. In the next chapter I move towards a theory of disruption, uncertainty, powerlessness and restoring equilibrium within children's and young people's experiences of being in hospital.

CHAPTER 10:
DISCUSSION

CHAPTER 10: DISCUSSION

Introduction

In this ethnographic study I explored 46 children and young people, aged from 5 to 16 years, experiences of being in hospital. The children and young people involved in the study held diverse experiences around both acute and chronic illness and being in hospital[21]. The guiding question of the study was to explore children's and young people's experiences of being in hospital within one hospital setting.

This chapter comprises of a theorisation about disruption, uncertainty, powerlessness and restoring equilibrium.

Towards a theory of disruption, uncertainty, powerlessness and restoring equilibrium within children's and young people's experiences of being in hospital

In Chapters 3 and 9, I highlighted the multiple factors and people impacting upon children's and young people's experiences of being in hospital. Further complexity is added by the ways in which the structure and organisation of children's services impact upon these experiences. This multitude of factors and complexities was influential in my choice of a theoretical approach to framing my findings.

In my search to create a synthesis of the findings I realised that the theoretical model needed to convey the interplay of different influences *on and by* the child, including experiences of disruption, powerlessness and uncertainty, and the way these interacted. I also wanted to be able to explain why some factors or influences appeared to be more powerful than others and how the child was not simply passive. I firstly turned to family nursing theory (Whyte 1997) as a theoretical framework for explaining my findings. This theory views the family as the unit of care within nursing practice and acknowledges that the family is situated within wider social worlds. However, whilst this offered promise through its acknowledgement of these wider social worlds and their subsequent interplay on children's and young people's experiences, it failed to take into

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[21] Although my study included children and young people from a wide range of ages and both acute and chronic illnesses I have referred to but not categorised the children and young people according to these factors. The findings and discussion of this study explores and focuses on the ***experiences*** of children and young people.

account the structural and organisational context of children's services and the ways in which these directly impact upon children and young people whilst in hospital.

Having considered a variety of existing frameworks I realised that my interpretation and synthesis had resonance with the work of Bronfenbrenner (2005, 1979). Whilst Bronfenbrenner's approach has primarily made its contribution to social care, it appeared that Bronfenbrenner's model provided the opportunity to explain the ways in which the multiple people and factors within the different layers[22] influenced, interacted and overlapped within children's and young people's experiences of being in hospital alongside the cascading effects of disruption, powerlessness and uncertainty. This is of significance as whilst I have previously discussed experiences of disruption, powerlessness and uncertainty in an almost linear fashion, in reality these overlap each other and are affected by and affect different layers. As such, the work of Bronfenbrenner offered insight into how disruption within one layer affects and impacts upon other layers. For example, how disruption experienced by being in the unfamiliar environment of the ward related to experiencing increased powerlessness and uncertainty when undergoing treatment and experiencing further powerlessness when being separated from parents and family. The acknowledgment of the ways in which children's services and policies impacted upon children, parents, families, staff and the ward setting and thus shaped the circumstances of children's and young people's experiences in hospital is an integral element of this study. Unlike Whyte's (1997) family systems model, Bronfenbrenner's work acknowledges the impact of the wider context upon children's and young people's experiences which is of consequence to my findings. Of consequence also is the way in which Bronfenbrenner's perspective accommodates the transitions and changes within children's and young peoples' lives.

As described in Chapter 2, Bronfenbrenner's approach conceives the world as a series of interactive ecological levels, based upon the combination of the child's biological disposition and environmental forces coming together to shape the child's experiences. Therefore, applying Bronfenbrenner to my findings, the children and young people, their parents, family, friends, and the ward, hospital and the context of children's services would be positioned within the different layers. Bronfenbrenner's approach has been depicted pictorially in a series of concentric circles where the smallest circle in the

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[22] This relates to the ways in which children and young people, parents, family, friends, nurses, medical staff, organisation of the ward setting, structure of the hospital environment and the context of children's services connect upon and affect one another.

centre of the others is the child (see figure 2.1 on page 18). The sense of the child being nested centrally appealed to the approach I had taken throughout my research from planning, design, fieldwork to interpretation. Centring the child also has resonance with the best nursing practice which places both children and young people and their accounts centrally to care delivery.

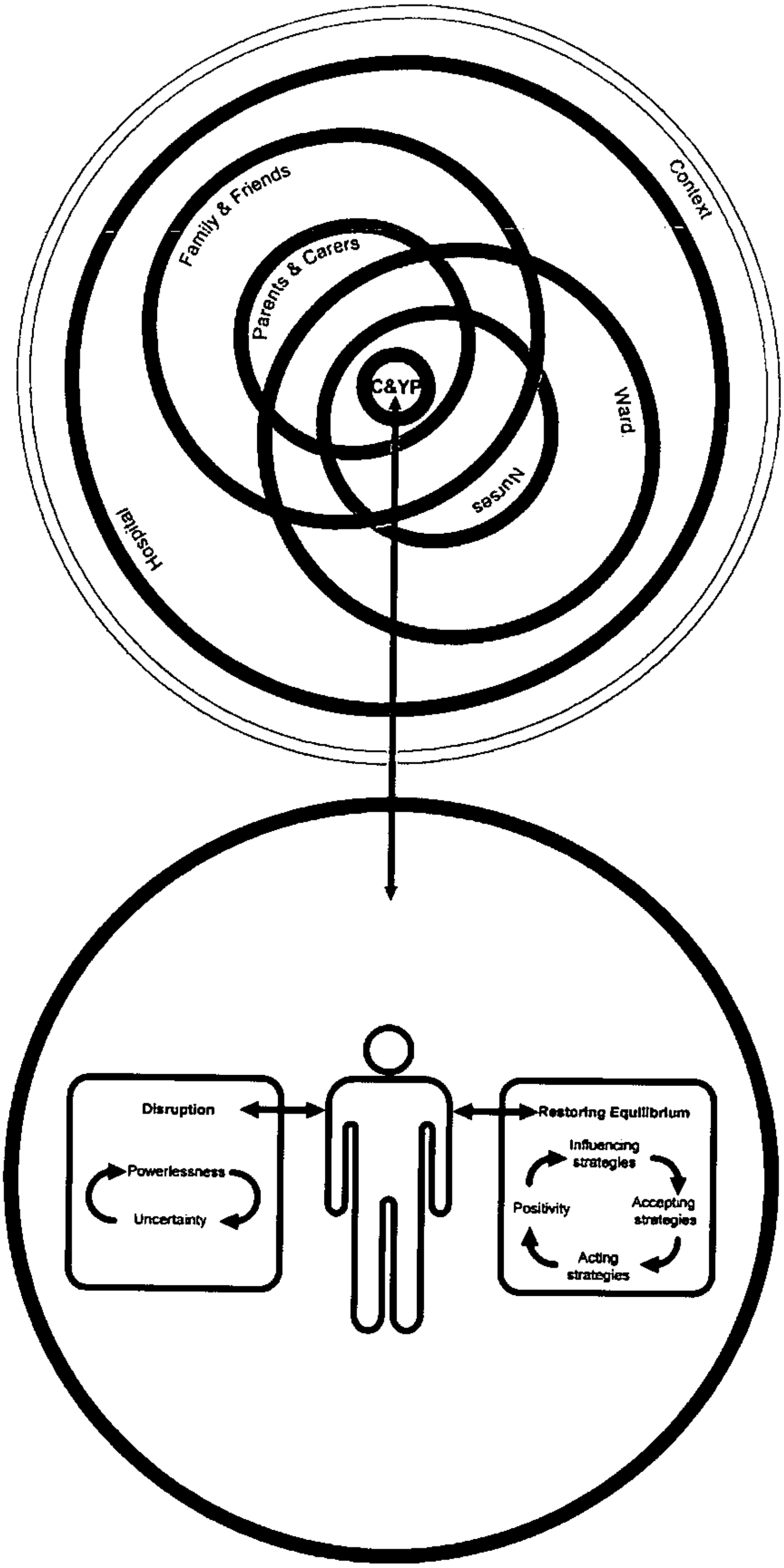
Bronfenbrenner's work offered promise to the way I was trying to theorise the importance of the connections between the immediate social settings, termed the mesosystem, in which a child is situated and the outermost systems, termed the exo and macrosystems, in which children and young people do not play a direct part but which nonetheless have a significant effect upon their experiences.

As discussed earlier, the framework of choice needed to take into account the structural organisation of children's services and the ways in which these affected children's and young people's experiences. Bronfenbrenner's acknowledgement of the cascading effect of change or conflict through all layers was essential as it provided a way for me to present and explore the multitude of factors at ward, hospital and wider contextual level impacting upon the ward setting, staff, parents and families and ultimately affecting children's and young people's experiences. Conceiving children's and young people's experiences in this way allowed me to recognise the integral part that context plays within the hospital setting and the ways in which this impacts upon experiences.

The notion of disruption, powerlessness and uncertainty and their associated influences cascading through all layers has further significance to my findings in terms of how this contributes to and is interrelated to the negative conceptualisations of children and young people as incompetent, powerless and dependent (as discussed in chapter two) which exist and which impact upon children's and young people's experiences.

Lastly, I needed to be able to acknowledge that children and young people are affected by, as well as affect, many different elements both proximal and distant to them. The multiple layers of Bronfenbrenner's model provided a good starting point and although I was attracted to Bronfenbrenner I realised that, for my purposes, it was limited. Additionally I needed a framework that would allow me to oppose the negative conceptualisations of children and young people by drawing attention to the capacities of children and young people in mediating the effects of disruption, powerlessness and uncertainty by attempting to restore equilibrium.

In figure 10.1 I develop Bronfenbrenner's work in relation to my findings by challenging the neat concentric circles of the existing Bronfenbrenner model through the ways in which disruption, powerlessness, uncertainty and restoring equilibrium interact upon on and cascade through children's and young people's experiences in hospital. The concentric neatness of the layers of Bronfenbrenner's model and the balance which appears to be evident was not apparent in my findings and did not adequately represent the disrupted lives I had learned about. In order to illustrate this, within figure 10.1 the (diagrammatical) layers are no longer balanced, tidy and neat but overlapping circles that cross over as multiple influences vie to take position. [*Note: Within this diagram the sizes of the circles are not relevant; that is they do not reflect importance or significance but are instead a way of representing the multiple layers impacting upon experiences. The diagram depicts the interrelated connections and the ways in which the different layers affect and are affected by each other]*. Importantly, the study is of children's and young people's experiences on a typical children's ward, where children and young people who had spent extensive time in hospital shared their perspectives of being in hospital alongside those encountering their first admission. Subsequently, the diagram reflects their generic experiences. Figure 10.1 reflects the ways in which the concepts of disruption, powerlessness, uncertainty and restoring equilibrium are working dynamically within, between and across all layers.



*** Disruption (uncertainty and powerlessness) and restoring equilibrium are dynamically working within, between and across all levels.**

Figure 10.1 Disruption (uncertainty and powerlessness) and restoring equilibrium

Table 10.1 depicts the ways in which the layers within my diagram draw upon the interactive ecological layers within Bronfenbrenner's approach.

Table 10.1 Relationship of Figure 10.1 to Bronfenbrenner's interactive ecological layers

Relationship of circles to people and settings within my model	**Relationship of layers to Bronfenbrenner's interactive ecological layers**
"parents and carers" relates to mothers, fathers, or main carers;	Microsystem (ward)
"family and friends" acknowledges the central role of siblings, grandparents and extended family[23] alongside friends, both those friendships developed within the hospital setting and outside of it;	
"nurses" reflect the nursing staff involved in children's and young people's experiences within the ward;	
"ward" and "hospital" relate to the settings in which the study was undertaken and include medical staff.	Exosystem (hospital)
The outer layer "context" acknowledges the contextual circumstances in which children's services are organised and delivered.	Macrosystem (context)

In the next section I discuss figure 10.1 by using examples from my findings, in order to illustrate the ways in which disruption, powerlessness and uncertainty impacted upon children's and young people's experiences. I include also the strategies undertaken by children and young people in an attempt to restore equilibrium.

Disruption and restoring equilibrium: The influence of the exosystem (hospital) on children's and young people's experiences

The hospital setting was an important factor that influenced children's and young people's experiences and it formed part of the exosystem (see figure 10.2). Whilst previous studies have tended not to focus upon the hospital setting, my study reveals that the context of the hospital was central to children's and young people's experiences within the ward.

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[23] This reflects the shifting construction of family in contemporary society.

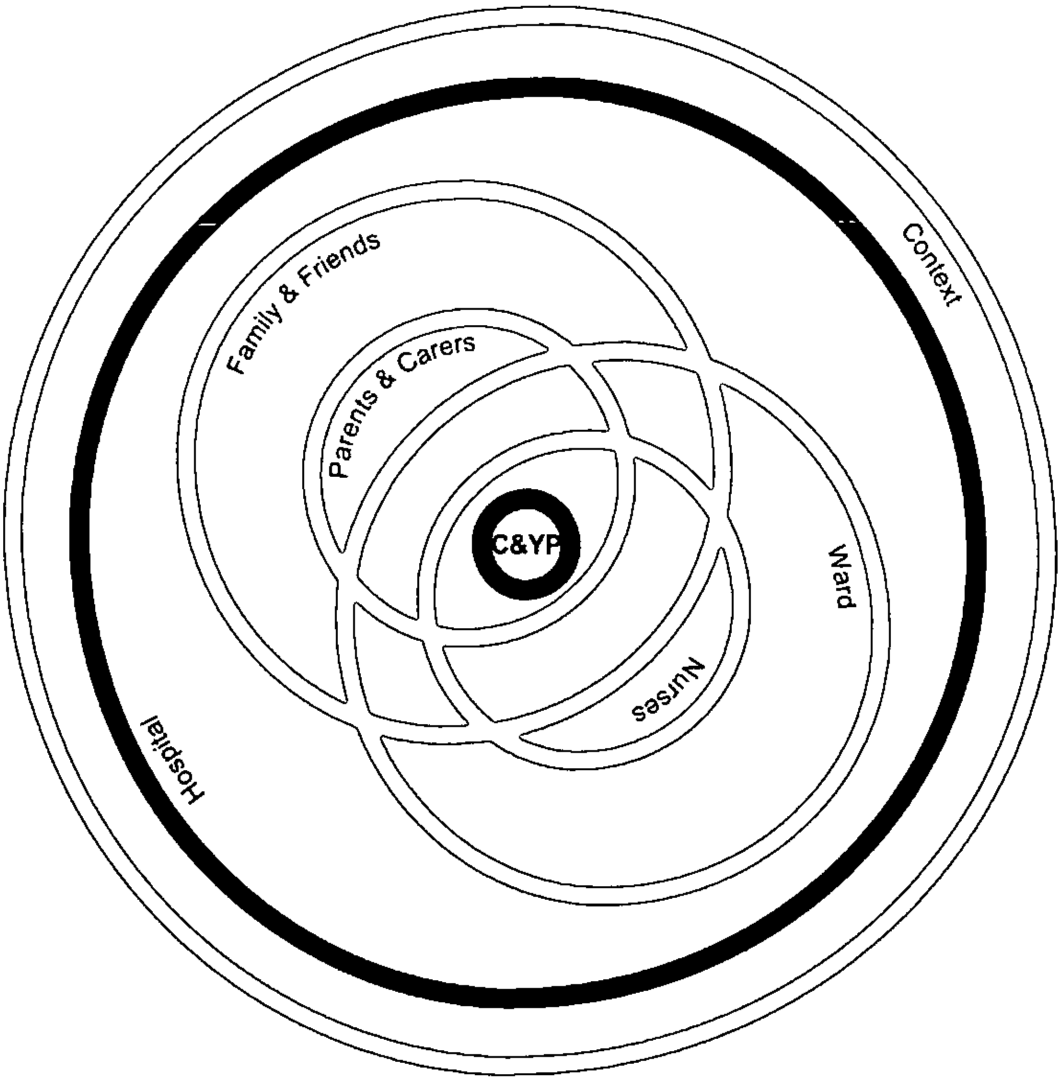

Figure 10.2 Disruption and restoring equilibrium: The influence of the exosystem (hospital) on children's and young people's experiences

As described in Chapter 8, the hospital within which the study was set had undergone radical change just prior to the research being undertaken. This resulted in wards being reconfigured and restructured, leading to fewer nurses being available on wards which had more beds. The effects of these changes were recognised by many children and young people who knew the hospital prior to these changes being made with several children and young people highlighting the impact of these changes upon both themselves and the nursing staff. The hospital setting is illustrated within the diagram as the exosystem. This is defined by Bronfenbrenner as the settings or contexts in which the child does not play a direct part but in which significant decisions are made affecting those individuals who do interact directly with the child. Therefore this recognises the contexts in which local decisions are made that impact upon children's and young people's experiences in hospital including for example, reconfiguration and hospital policies impacting upon care provision and visiting. The reconfiguration impacted negatively upon both staffing levels and the building of relationships between children and young people and nurses, for example Samuel (41) [pages 188-189] and Isabelle (20) [page 190], thus indicating a clear and direct link evident to the children and young people between the disruption they experienced and the hospital layer.

Children's and young people's accounts revealed disruption where care provision and the development of relationships with nurses were negatively affected due to the reconfiguration; being cared for by multiple nurses greatly reduced the opportunities open to staff to learn of their individual care needs, preferences and anxieties. This led to children and young people feeling uncertain about their care and increased feelings of powerless. Whilst the decision to reconfigure the ward setting was made at a local level, the ensuing (ecological) disruption engendered uncertainty and powerlessness which cascaded through to children and young people within the ward. Three decades ago, Stacey (1976) commented that "rather than conceiving of the hospital as a rational organisation designed to facilitate treatment with the greatest possible efficiency, the hospital should be conceived as a social organisation which is full of discontinuities for the child patient, which fragments the child and his/her care, which is resistant to change, and where information control is used to maintain the status quo" (Stacey 1976: 198). Whilst it is of concern that these findings parallel the experiences of children and young people in hospital within this study over thirty years later, this study offers the opportunity to explore this alongside the multi-factorial and overlapping experiences of disruption, powerlessness and uncertainty impacting upon children's and young people's experiences whilst in hospital.

In an attempt to reduce the disruption, uncertainty and powerlessness experienced, children and young people undertook a range of strategies in order to restore equilibrium. These included for example, accepting that hospital was the "best place" for them in order "to get better" or "get back to normal" and thinking positively about being in hospital by both "acquiring optimism in the face of adversity" and identifying positive instances during their time in hospital and reflecting upon these. For some children and young people, acquiring optimism in the face of adversity led to them identifying and exploiting the positive effects of being in hospital, for example, Stephen (43) [page 137]. For others, complying with necessary treatment regimes and the social order of the ward aided the restoration of equilibrium, supporting previous work in hospital and health care settings suggesting that when contending with the power structures imposed upon them, children learn that compliance, acceptance and conformity are necessary for survival (Beuf 1979, Mayall 1995).

Disruption and restoring equilibrium: The influence of the microsystem (ward) on children's and young people's experiences

As illustrated within figure 10.3, children and young people were encompassed within the ward setting.

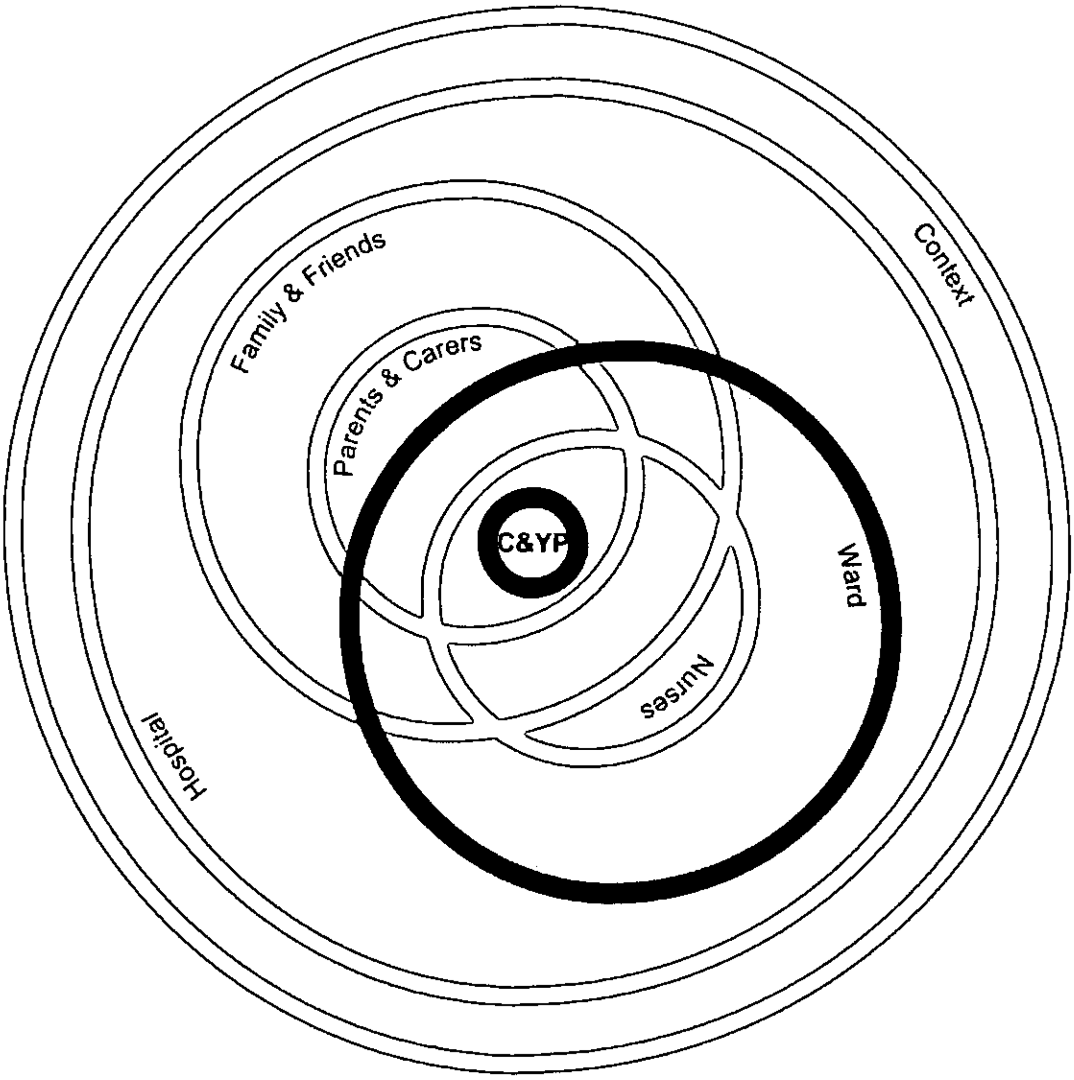

Figure 10.3 Disruption and restoring equilibrium: The influence of the microsystem (ward) on children's and young people's experiences

Children's and young people's accounts clearly revealed that they had little control over the organisation of care and ward routines whilst they were in the ward. It appeared that where care was routinely organised, both the inflexibility and uncertainty of the ward social order were at odds with the children's and young people's usual everyday routines leading to a lack of control and subsequent feelings of powerlessness. For example, Anna (2) [page 113] and Louise (27) [page 125]. Thus my findings support work by Beuf (1979: 54) that for children in hospital "the simplest acts become regimented in the total institution, thus undermining even further the patient's sense of self-determination".

Some children and young people highlighted a lack of consultation between themselves, their parents and nursing staff about their involvement in care which led to conflict, for example, Florence (14) [page 200]. Similar conflicts around parental involvement in care arising from restrictive ward routines and policies have been highlighted previously within the literature (for example, Sands 1996). Further, Darbyshire (1994) highlights parental participation often occurred because they believed it was expected of them and assumed to be the case by nursing staff. Whilst findings support these previous studies, I additionally and importantly reveal experiences of expectations being placed upon children and young people. However, the organisation of care based around routine further limited children's and young people's abilities to influence their care and who was involved in this, resulting in disruption and powerlessness. Each of these elements; routinisation of care, disruption and powerlessness, have important repercussions upon meeting children's and young people's rights whilst they are in hospital.

The findings suggest that the needs of the social order of the ward could be interpreted as being more important than the needs of children and young people, supporting previous work by Knafl, Caballari and Dixon (1988). The loss of their usual routines led children and young people to experience feelings of disruption, uncertainty and powerlessness. Other work (see Gusella, Ward and Butler 1998) has similarly reported loss of control as being particularly significant for adolescents in hospital. Other studies meanwhile have described the demands and constraints of the social order on children and parents (see Beuf 1979), suggesting that children and parents experience stress and disruption from trying to fit into the social order of the ward (see Coyne 2003). My study supports the findings of Coyne in that despite the child being the focus of care and the object of everyone's attention and activity children and young people themselves had little control over the organisation of care and events.

Recent Government standards which have described fundamental changes in health care services as moving towards "a cultural shift to services designed and delivered around the person using those services, and not around organisations" (Department of Health 2003: 4). Indeed, Standard 3 of the National Standards Framework Core Standards (Department of Health 2004) advocates the provision of care that is child centred, considered within the context of children's and family's needs and taken in account of family's unique needs and their views. Despite this policy which one might expect to have strongly influenced the exosystem, this does not seem to have permeated through to the microsystem. This contrasts strongly with children and young people's experiences of the ward setting as being unfamiliar and inflexible to their specific and individual needs.

In contrast to the adult oriented, dominant practices within the ward setting, the children and young people adapted strategies to mitigate the disruption to their lives. In many instances the disruption was accommodated as they got used to or went along with negative aspects of being in the ward. Other children and young people reduced feelings of loneliness and isolation by maintaining individual routines which required them to influence ward routines.

Disruption and restoring equilibrium: The importance of the macrosystem (context) on children's and young people's experiences

The context was an important element impacting upon children's and young people's experiences and it formed part of the macrosystem (see figure 10.4). The macrosystem recognises how children's services and policy are both organised and delivered thus shaping the circumstances in which hospital and ward settings operate. Whilst much of this policy aims to engage and empower children and young people, this political rhetoric is not always successfully implemented and is often contradictory.

Within his approach Bronfenbrenner acknowledges that the effects of the larger principles within the macrosystem have a cascading influence through the other layers, in turn affecting and effecting the structures in which people function. These effects cascade towards the child within the context of their microsystem in turn setting the context in which children's and young people's experiences were set. My diagram reflects Bronfenbrenner's work in acknowledging the cascading effects of policy (and concomitant disruption, powerlessness and uncertainty from the wider context) through the hospital and ward settings onto staff, parents and families, impacting directly on children and young people.

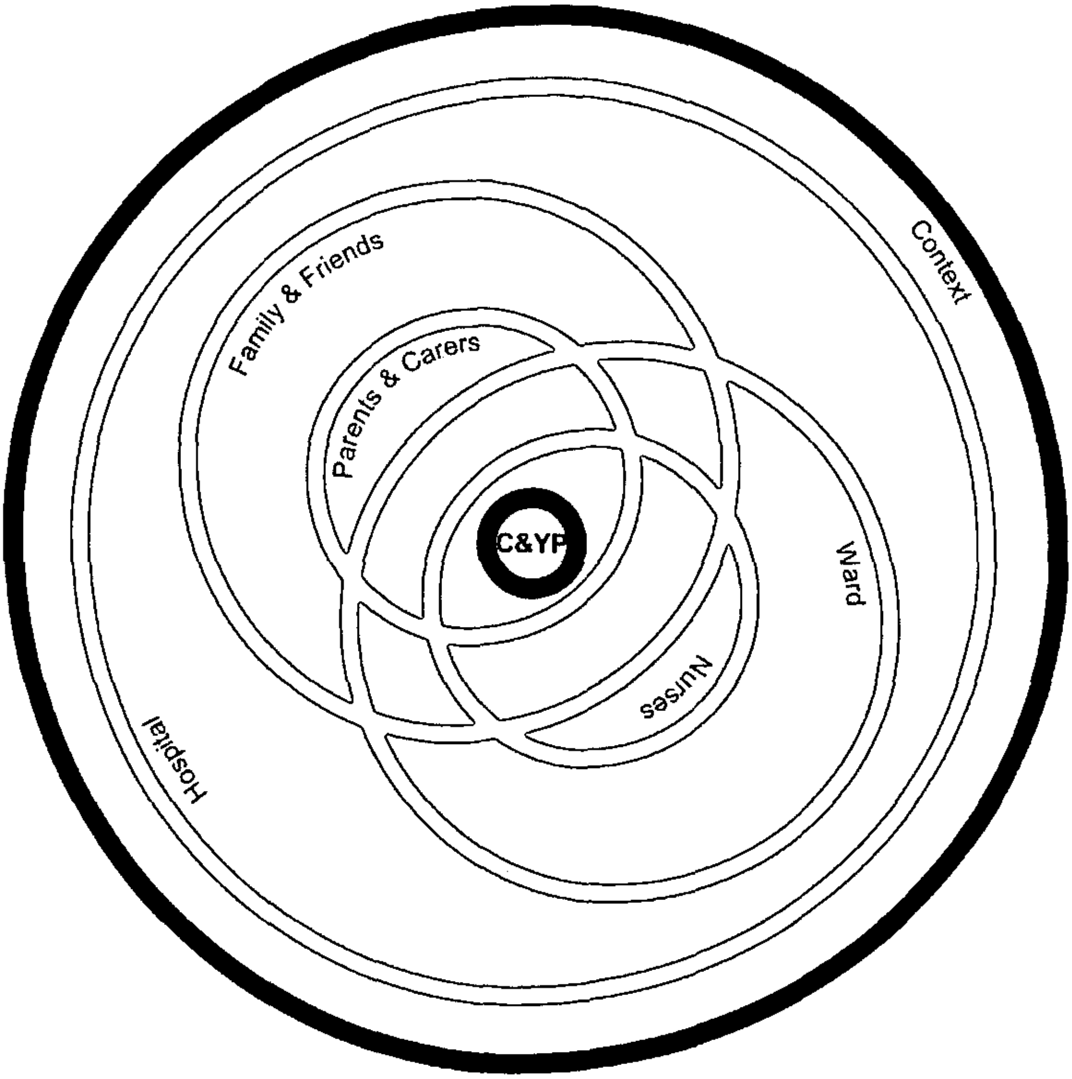

Figure 10.4 Disruption and restoring equilibrium: The importance of the macrosystem (context) on children's and young people's experiences

Children and young people within the study highlighted the constraints they recognised were in existence. These related to care provision, for example Samuel (41) [page 188]. This increased capacity alongside reduced staffing levels appeared to have a grave impact upon the perceived delivery of nursing care to children and young people supporting other work which has suggested that organisational arrangements and economic restraints are often prioritised above best patient care (Whittemore 2000). Many talked of being cared for by different nurses on a daily basis. The children and young people expressed that this inhibited nurses' abilities in building up relationships with children and young people and resulted in many feeling that nurses were unaware of their needs, at both an individual and treatment level, for example, Charlotte (8) [page 189]. This supports other work which has suggested that having a consistent nurse carer could help to make hospitalisation more bearable for children (Coyne 2003).

The constraints imposed upon the nurses through low staffing levels and bigger wards resulted in children and young people feeling responsible for ensuring that they received the correct care and treatment on time. Feeling responsible for their care led to children and young people being observant of care and procedures undertaken by nurses in order to ensure that these were performed satisfactorily. The burden of responsibility around care led to resentment when having to remind the nurses about medications and procedures as often this could lead to bad feeling and conflict, for example, Elena (11) [page 204]. This resulted in a "double bind" whereby children felt that they wanted to trust and develop relationships with staff but instead had to "chase" or "hassle" them regarding their care. Undertaking this co-ordination of care did not appear to be sought by any of the children or young people but instead seemed to be imposed upon them due to the aforementioned constraints. As a result, many children and young people appeared to feel frustrated and resentful about this responsibility. Meanwhile, these conflicts around care and the expectations enforced upon children, young people and their parents led to feelings of disruption and uncertainty around the provision of care leading to increasing feelings of powerlessness.

Whittemore (2000) describes the ways in which care delivery often acts to the detriment of relationships being built between nurses and patients. This includes the redistribution of nursing staff with fewer nurses caring for a greater number of patients, with healthcare assistants providing much of the direct patient care. Previous work has likened the child to being an object that had things done to it, rather than being involved or having a voice (Knafl, Cavallari and Dixon 1988) with these authors concluding that the bureaucratic organisation, nurses, doctors and other health professionals had significantly more influence than children. Similarly in a synopsis of the literature around patients' experiences with nursing, Kralik (1997) found that patients experienced feeling uncared for and depersonalised when nurses approached them as an object to which nursing actions were applied. This resonates strongly with children's and young peoples' negative experiences.

Where children and young people recounted times where they felt care had been poor, many recognised and acknowledged the constraints that existed upon staff and used these as a rationale and this aided them to restore equilibrium. For example, many highlighted the low nursing staff levels and the large busy wards in an attempt to counterbalance reasons why medications might be late or treatment waited for. In some instances, young people gave examples of poor care but then countered these with defending the nurses, drawing attention to the difficult situation they were in, for example, Callum (6) [page 209].

Callum's comments highlighted that it was not just children and young people who were affected by the constraints in existence. Children's nurses also were negatively affected by being unable to provide the level of care they wished to. Work by Coyne (2007) indicates that nurses may seek to make children compliant with the ward social order due to lacking control over issues such as bed occupancy, throughput and turnover, all ultimately affecting their workload. Thus nurses may feel pressurised by institutional demands placed upon them with non-compliant children (and parents) significantly threatening their control over workload and time demands and rendering them powerless. Bronfenbrenner's approach provides a way to understand how the cascading effects of policy affect all those who come into contact with children and young people in hospital and the ways in which this translates into disruption, powerlessness and uncertainty not just for children, but also for those involved in their care.

Summary

In this chapter I have moved towards a theory of disruption, uncertainty, powerlessness and restoring equilibrium within children's and young people's experiences of being in hospital. In the next chapter I present the limitations of the study, implications for practice and future research, dissemination of the findings and the conclusion.

CHAPTER 11:
CONCLUSION

CHAPTER 11: CONCLUSION

Introduction

In this chapter I present an overview of the limitations of the study. This is followed with the implications for both practice and future research, and strategies for dissemination of the findings. I next outline my reflections upon the methods used within the study. Lastly, I present my concluding thoughts.

Limitations of the study

Whilst the study fulfilled the guiding question by providing an account of children's and young people's experiences of being in hospital within one hospital setting, I recognise that certain limitations exist. In this following section I plan to critically consider both what I perceive to be the key limitations to the study whilst placing these limitations in the context of the existing literature and proposing how such limitations could be addressed in future work. The key limitations I will address here include sample size, study setting and the diversity (and lack of diversity) of the children who participated. Further I will address the impact that solely focusing on the children's and young people's experiences without including the voices of parents and professionals to help triangulate an understanding of experiences.

Inevitably the sample size is small in comparison to the total number of children and young people in hospital, although in terms of the number of children and young people involved, the study itself is one of the largest qualitative studies on children's and young people's experiences of hospitalisation carried out to date in the UK. Furthermore, although children and young people often drew on their experiences of wards and hospitals other than the study setting and a variety of clinical areas such as theatre and intensive care, the study is primarily based upon experiences within one ward setting within one hospital. As the setting was within a children's hospital, their experiences may differ from those of children admitted to and receiving care within district general hospitals where a considerable amount of care is currently delivered. Consequently, further study into children's and young people's perceptions of other settings such as hospices, respite environments and experiences of receiving care within the home setting may yield further understanding of experiences in these more personal settings, in particular highlighting if disruption, powerlessness and uncertainty are experienced also within these environments. Similarly, studies into experiences of receiving care within the home setting from the perspectives of children and young people may reveal if disruption is lessened within the home environment and offer valuable insight into how this may be transferred into hospital settings.

The study encompassed children and young people from a wide range of ages and illnesses, both acute and chronic. In this sense the children were diverse in terms of their experiences and what they brought with them to their period of hospitalisation. Although I have emphasised this diversity as a strength of the work and a facet of its originality I am aware it does also create a level of limitation. Thus further work around more focused age groups and particular illnesses may illuminate experiences specific to both age and illness. Alternatively, more work with similarly diverse groups of children in other hospital wards could help establish whether children admitted to mixed/non-specialist children's wards in other hospitals have similar experiences and draw on similar active strategies.

Importantly, whilst I have emphasised the diversity of the participants, they were similar in one particular and important way, they all had to speak English. This in and of itself is a limitation considering the multi-cultural nature of contemporary society and means that this study can only reflect the experiences of English speaking children and young people. Similarly children and young people who were unable to express themselves verbally were unable to be included, albeit that care was taken to include children and young people who are often marginalised within research, such as those with on-going illness or learning disabilities. Thus whilst this study has aimed to provide voice to children and young people and has to a large degree extended the opportunity for children's and young people's voices to be heard, future work should include children and young people who are not able to speak English and those who are unable to express themselves verbally. This is important, not least because they may potentially have the most disrupted and uncertain experiences of hospitalisation and have less powerful positions from which to exert their own social agency.

Whilst it was my intention to explore the experiences of children and young people specifically, I am aware that further study in the ward setting drawing upon the perspectives of both health professionals and parents may add clarity to the complex nature of the multiple people and factors impacting upon children's and young people's experiences of being in hospital. However, I stand by my decision to privilege children's and young people's voices in this study. If I had not done this it is perhaps possible that the original insight into how they mediate their hospitalisation would have not resonated so strongly in my findings.

Despite the limitations I have identified, the findings from this study are important, original and have implications for practice. A clear appreciation of the implications and how they can be translated into practice and how they might influence future research is an essential component of any practice-oriented study. These implications are outlined in the following section.

Implications

The study has many implications for the development of services that are orientated towards children and young people in order to meet their needs whilst they are in hospital. These are likely to have resonance not just for the study but also for wider services for children and young people in hospital. A summary of implications for both practice and future research are provided below.

Implications for practice

The implications for practice are outlined in three sections; context of care, engaging with children and young people and nursing practice. In each section I provide an overview summary of the implications and follow this with extended bullet points about specific ways in which my findings could (and I would argue should) contribute to best practice.

Context of care

Drawing upon Bronfenbrenner's model, the findings revealed that the context within which the ward was based was central to children's and young people's experiences within the hospital setting. For example, children and young people with both acute and chronic illnesses highlighted the disruption, powerlessness and uncertainty they experienced in relation to care practices when being admitted to hospital. Thus, applying Bronfenbrenner's approach to clinical practice would cross the boundaries of hospital and home. This would potentially minimise disruption by drawing on children's and young people's usual daily strategies, for example, by adopting individual everyday routines within the hospital setting. For children and young people with long term or complex illnesses, the integration of routine services would aid in the provision of seamless care to this important group by cutting across the different contexts within which care is provided, such as home, hospice or respite setting, ensuring that individualised treatment and care is provided.

The influence of the context of care is important as are the ways in which children's services and policies impacted upon children and young people within the ward setting as these both shaped their experiences in hospital. Whilst it could be argued that various competing systems make it impossible to give care in the way that best policy often espouses, the application of an ecological approach highlights the multiple layers impacting on children's and young people's experiences within hospital, for example, by the reconfiguration of wards and the resultant effect on care delivery.

Thus, best practice would aim to:

- Acknowledge that the child's experiences of being in hospital are part of a wider set of experiences and influences and that the ward is nestled and part of the hospital setting which is part of the wider community. Nurses should be aware of and accept some level of responsibility for ensuring that the child's journey to the ward (from approaching the hospital, to entering the hospital, to moving down corridors to entering the ward and experiencing the routines on the ward) is as child friendly as possible.
- Provide continuity of care in order to promote nurses' awareness of individual children/young people's preferences and care needs in order to reduce the disruption and uncertainty experienced. The importance of integrated service provisions where feasible should be a regulatory ideal. This would seem to be of particular importance for those children and young people with chronic and long standing illnesses who clearly expressed nostalgia for the old ward setting in which they had established and reciprocal relationships with nurses to ease their periods of hospitalisation.
- Adapt ward routines to become more flexible to the individual needs of children and young people in order to lessen the disruption, uncertainty and powerlessness experienced.

- Acknowledge that many children/young people with chronic and complex illnesses have expert knowledge of their illness and its management and utilise this within the hospital setting in order to reduce disruption and powerlessness. This could be achieved by providing opportunities for children/young people with chronic and complex illnesses and their parents to continue with individual daily management routines whilst in hospital. Whilst this implication is not perhaps new it is important to reiterate it here as chronic and complex care is no longer "contained" within specialist units where handing over daily management routines is relatively easy to manage. Within mixed wards with a high patient turnover, different acuities of patient need and diverse diagnoses supporting daily management routines is challenging but based on my findings it is an essential aspect of care management to address.
- Give children/young people the opportunity to become "expert patients" by enabling them to develop the skills needed to deal with their condition, and thus reduce feelings of uncertainty and powerlessness.

Engaging with children and young people

The study revealed the importance of engaging with children and young people in the hospital setting in an ecological way. This could involve the implementation of child centred documentation for children and young people to engage with in order to ensure that they are fully involved within their care and treatment. For example, the implementation of child/young person centred assessment tools could distinguish normal daily routines in order to ascertain those factors which may lead to disruption within the hospital setting, such as the late administration of medications. This documentation could also be adapted to enable children and young people to provide consent to procedures by assessing their understanding of their condition and its treatment. Meanwhile, enabling children and young people to provide feedback on the care and treatment they receive would also enhance future care of children and young people and ensure that services are delivered taking into account children's and young people's perspectives. Similarly, ascertaining individual coping strategies would both enable children and young people to more effectively restore equilibrium when necessary and give children's nurses the knowledge and skills to empower children and young people to do this. This builds on the previous best practice statement by nurturing children/young people as "expert patients", thus recognising self agency and respecting the rights of children and young people.

Thus best practice would aim to:

- Seek the views of children and young people in appropriate ways in order to take into account the views of children and young people in the planning, delivery and evaluation of services. This would include promoting the inclusion of children and young people who are often excluded including those with disabilities, long term needs and children/young people who are unable to communicate verbally. Importantly, although the inclusion of children's and young people's views in terms of planning, delivery and evaluation of services is now part of the rhetoric of care I am arguing that this engagement should be not be constrained to occasional audits and consultations but should become embedded into everyday practice. Nurses should be engaging with children and young people using child centred tools to find out and reduce those things that might be individually disruptive as well understand the strategies and mechanisms individual children/young people utilise to mediate difficult experiences and provide means to promote their use.
- Recognise the ways in which undergoing treatment impacts upon children/young people, particularly in terms of the disruption and powerlessness it incurs and through using an ecological approach to work with the children to mediate these.
- Provide diagnosis, illness and treatment options information to children/young people in order to reduce the disruption and powerlessness experienced by enabling their involvement in treatment decisions and participation in care planning/delivery.
- Give access to information that is relevant, up-to-date, ethical and understandable according to ability and culture directly to children/young people themselves, in order to minimise disruption, uncertainty and powerlessness around illness and treatment procedures.
- Recognise the importance of restoring equilibrium and attune nursing care to finding ways of supporting and facilitating children's/young people's own strategies.

Nursing practice

An awareness of the factors that lead to disruption, uncertainty and powerlessness for children and young people within hospital would enable children's nurses to practise in ways in which this could be reduced. Conversely, by increasing children's nurses understanding of the active strategies used by children and young people within the hospital setting in order to restore equilibrium would enable them to better mitigate the disruption experienced whilst in hospital.

Children and young people described the attributes they believed are characteristic to being a "good nurse". The findings indicated that often these "good nurses" reduced children's and young people's feeling of disruption, powerlessness and uncertainty by, for example, spending time developing positive relationships with them. Thus practicing in the way advocated by children and young people could reduce the disruption experienced and empower them in restoring equilibrium.

Thus, best practice would aim to:

- Educate children's nurses in relation to those factors which lead to disruption for children and young people within the hospital setting and enable them to develop skills in order to practise in ways which minimise disruption and/or enable children/young people to restore equilibrium.
- Organise and deliver care in ways in which reduce the disruption, uncertainty and powerlessness experienced by children and young people.
- Increase understanding of the active strategies children/young people use to restore equilibrium in order to enable them to better mitigate the disruption experienced whilst in hospital.
- Ensure that the characteristics and behaviours children/young people believe are characteristic to being a "good nurse" become part of the vision of care within ward settings.

Implications for future research

The implications for practice offer several directions for future research to take including:

- Qualitative research into children's/young people's experiences of being cared for in the hospital setting using an ecological approach in order to ascertain if this reduces the disruption, uncertainty and powerlessness experienced.
- Work evaluating children's and young people's perceptions of the methods of engagement utilised within qualitative research in order to determine the effectiveness of these and the degree to which children and young people feel that they are useful and suitable. This work could include further exploration of how the tools used to help "trigger" conversations and interviews with children enhance and/or otherwise change the type, depth and intensity of data generated.
- Studies into children's nurses' experiences of practicing within an ecological approach in order to elicit its effectiveness from a children's nursing perspective.

Reflections on the methods used

The study used multiple, child centred methods alongside semi structured interviews and unstructured participatory observation. These methods included play and a range of activity based techniques in order to enable children and young people within a wide range of ages, illness, abilities and learning and physical disabilities to express their perspectives. In comparison with some previous studies which have been dominated by adult-centric approaches to data collection offering little choice to participants, children and young people within the study were empowered within data collection through the opportunity to choose the methods with which they wished to engage.

The children and young people within the study revealed their competence in engaging with these methods in order to articulate their experiences. Drawing upon the success of the methods used, the techniques of data collection enabled children and young people to express their perceptions of being in hospital and are methods that can be used in future work. Preferences varied between individual children and young people, and across age, with some choosing to use a variety of methods and others preferring only to be interviewed and express their experiences verbally. Of those children and young people who chose not to participate in the activities, the majority were between 12-16 years, thus suggesting that younger children prefer to engage most with activities.

However, there was often a disparity between uptake of methods across ages thus indicating the importance of providing children and young people with choice in order to enable them to participate in research.

Table 4.2 depicts the activities used by children and young people[24]. Within the table children and young people with acute and chronic illnesses are listed separately in order to illustrate the choices made by those within each group. The table reveals that drawing (39.1%), play activities (23.9%) and the activity "Feelings about hospital" (23.9%) were the most widely chosen by both acutely and chronically ill children. However, whilst the latter activity "Feelings about hospital" was frequently chosen by children with acute illness (17.3%), children with chronic illnesses much less engaged with this (6.5%). "The activity "People who are important to me" was chosen infrequently by all children and thus may be of less value. It appears that girls engaged with the methods and activities used within the study more than boys. Whilst drawing was the most popular activity across gender (girls 21.7%, boys 17.3%), the second activity most widely chosen was the "Feelings about hospital" activity for girls (19.5%) and play activities for boys (8.6%).

A point I think, on reflection, is important to make is that whilst the multiple, child centred methods I used may appear simple to use, they required skill and sensitivity to develop and utilise within the practice-research setting. I drew on many of my children's nursing skills to utilise these effectively and undoubtedly these would have been less successful if used by a researcher who had less experience of working with children and young people.

The study has demonstrated the value of participant observation alongside multiple, child centred methods and interviews. The observational data was valuable in its own right and added clarity and understanding to the interview data. Furthermore, the period of observation offered an opportunity to view the ward setting through a research lens and attempt to get a sense of how it might appear to children and young people. It also provided instances where observed care was poor and at other times where practice was excellent. As a practising children's nurse I learnt a great deal from these experiences and have attempted to adopt and emulate the good approaches within my own practice.

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[24] See appendix 25 for a detailed summary of responses to individual activities.

Dissemination

I started my study with a passion and drive to find out more about children's and young people's experiences of being in hospital. From the conception of the study I wanted to be able to influence and enhance their experiences and where appropriate to change practice. Without an effective dissemination strategy my study will not be able to exert an appropriate influence. Therefore, it is intended to utilise a number of strategies to disseminate the findings of the study to children and young people, professionals and academics. These are outlined below.

- The distribution of information leaflets to the children and young people who participated in the study.
- The development of information sheets explaining the main findings of the study to health professionals of the Trust in which the study was carried out.
- The dissemination of the study findings through the University of Central Lancashire, School of Nursing and Caring Sciences website, aimed towards nursing students and academics.
- The submission of abstracts and posters to national and international conferences, related to methods, findings and practice.
- It is intended to prepare and submit papers for publication around the study findings relating to current practice, the delivery of children's services and methods for carrying out qualitative research with children and young people to a number of high impact journals.

Conclusion

This study has achieved and exceeded what it set out to do. It has engaged with a diverse group of children and young people brought together through admission onto a general children's ward and explored their experiences of being in hospital. It has avoided the limitations of previous studies in that it mirrors the real world of a general children's ward where children and young people with extensive experience of being in hospital are cared for alongside those with only minimal hospital experience. Using multiple, child centred methods it has taken an look *across* children's and young people's experiences. The lens of the study has been focused on the children and young people and their experiences not on their illness. It reflects a contemporary "slice" of life in a general children's ward in a typical children's hospital in the UK in the 21st century.

The findings of this study revealed that being in hospital disrupted children's and young people's lives. Alongside this disruption, both powerlessness and uncertainty were central experiences. Disruption occurred in a number of ways; as a result of being in the hospital setting itself, due to the restraints and invasiveness of illness and treatment and as a result of conflicts around care. However, children's and young people's accounts indicated their capacities through the strategies and actions they used in an attempt to restore equilibrium, thus counterbalancing the effects of disruption, powerlessness and uncertainty. This study contributes to current knowledge by bringing together the ways in which being in hospital creates disruption for children and young people and their agency and capacity in mediating their resultant experiences of powerlessness and uncertainty. By drawing upon Bronfenbrenner's approach, not previously applied within the acute child healthcare setting, this study reveals that the context of the hospital setting, alongside the wider influences of health care, are central to children's and young people's experiences. I also present a model to provide support to children and young people by reducing disruption, uncertainty and powerlessness and increasing the restoration of equilibrium whilst they are in hospital, adding to the current body of knowledge. This new knowledge gives children's nurses' direction for improving practice.

A core theme of The NHS Plan (Department of Health 2000) is to design and deliver services around the needs of those using them by seeing through the eyes of the children and their families. Research in a range of settings has depicted children and young people as competent and rational agents (Lindsay Waters 2008, Mayall 2000, Doorbar 1995), "who resist dominant discourses and create their own discursive spaces based on their own analyses and experiences" (Kelly 2005: 263). The accounts generated in this study describe being in hospital from the children's and young people's own perspectives. This study has further highlighted and explicated the agency and abilities of children and young people in restoring equilibrium against the disruption, powerlessness and uncertainty they experienced within the hospital setting.

With the agency and abilities of children and young people in mind, it is fitting therefore that the last words in this study are from one of the children. Violet, aged nine, is clear and easily able to articulate her perceptions of being in hospital. I hope that my research will help to make being in hospital better for children like Violet who explained:

> "I like being in hospital and I don't. ... It'd be good if being in hospital was better and then people like me wouldn't be sad at being here and I could enjoy the good bits more" (Violet, (44) aged 9 years).

REFERENCES

REFERENCES

Acker, J., Barry, K. and Esseveld, J. (1983) Objectivity and truth: Problems in doing feminist research. *Women's Studies International Forum,* 6, 423-435.

Alderson, P. (1993) *Children's Consent to Surgery.* London, Open University Press.

Alderson, P. (1995) *Listening to Children. Children, Ethics and Social Research.* Barnados.

Alderson, P. and Montgomery, J. (1996) *Health care Choices. Making Decisions With Children.* Institute for Public Policy Research.

Alldred, P. (2000) Ethnography and Discourse Analysis. Dilemmas in Representing the Voices of Children. In Ribbens, J. and Edwards, R. Eds *Feminist Dilemmas in Qualitative Research. Public Knowledge and Private Lives.* London, Sage Publications.

Appleton, J.V. and King, L. (2002) Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research. *Journal of Advanced Nursing* 40, 6, 641-648.

Archard, R. (1993) *Children: Rights and Childhood.* London, Routledge.

Atkin, K. and Ahmad, W.I.U. (2001) Living a "normal" life: Young people coping with thalassaemia major or sickle cell disorder. *Social Science and Medicine* 53, 615-626.

Baillie, L. (1995) Ethnography and nursing research: A critical appraisal. *Nurse Researcher* 3, 2, 5-21.

Balen, R., Holroyd, C., Mountain, G. and Wood, B. (2000) Giving children a voice: Methodological and practical implications of research involving children. *Paediatric Nursing* 12, 10, 24-29.

Barbour, R.S. (2001) Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? *BMJ* 322, 1115-1117.

Barker, J. and Weller, S. (2003) "Is it fun?" Developing children centred research methods. *International Journal of Sociology and Social Policy* 23, 1/2, 33-58.

Battrick, C. and Glasper, E.A. (2004) The views of children and their families on being in hospital. *British Journal of Nursing* 13, 6, 328-336.

Benner, P. (1984) *From Novice to Expert: Excellence and Power in Clinical Nursing.* Menlo Park, Addison-Wesley.

Benner, P. and Wrubel, J. (1989) *The Primacy of Caring: Stress and Coping in Health and Illness.* Menlo Park, Addison Wesley.

Beresford, B. (1997) *Personal Accounts. Involving Disabled Children in Research.* Social Policy Research Unit, University of York.

Berk, L.E. (2000) *Child Development.* Fifth Edition. Boston, Allyn and Bacon.

Berman, H. (2003) Getting critical with children: Empowering approaches with a disempowered group. *Advanced in Nursing Science* 26, 2, 102-113.

Beuf, A.H. (1979) *Biting off the Bracelet: A Study of Children in Hospitals.* Philadelphia, University of Pensylvania.

Bluebond-Langer, M. (1978) *The Private Worlds of Dying Children.* Princeton, Princeton University Press.

Blumenreich, M. (2004) Avoiding the pitfalls of "conventional" narrative research: Using post-structural theory to guide the creation of narratives of children with HIV. *Qualitative Research* 4, 1, 77-90.

Blumer, H. (1969) *Symbolic Interactionism: Perspective and Method.* New Jersey, Prentice Hall.

Boemmel, J. and Briscoe, J. (2001) *Web Quest Project Theory Fact Sheet of Urie Bronfenbrenner.* Available from: {http: //pt3.nl.edu/boemmelbriscoewebquest.pdf} [Accessed 18 September 2009].

Boyden, J. and Ennew, J. (1997) *Children in Focus. A Manual for Participatory Research with Children.* Radda Barnen.

Bricher, G. (1999) Children and qualitative research methods: A review of the literature related to interview and interpretive processes. *Nurse Researcher* 6, 4, 65-77.

Bricher, G. (2000) Children in the hospital: Issues of power and vulnerability. *Pediatric Nursing* 26, 3, 277-282.

Bronfenbrenner, U. (1979) *The Ecology of Human Development. Experiments by Nature and Design.* Cambridge MA, Harvard University Press.

Bronfenbrenner, U. (1990) Discovering what families do. In Blankenhorn, D., Bayme, S. and Elshtain, J.B. Eds. *Rebuilding the Nest: A New Commitment to the American Family.* Milwaukee, Family Service America.

Bronfenbrenner, U. (2005) *Making Human Beings Human. Bio-ecological Perspectives on Human Development.* London, Sage.

Brook, G. (2000) Children's competency to consent. *Paediatric Nursing* 12, 5, 31-35.

Broome, M. and Stieglitz, K. (1992) The consent process and children. *Research in Nursing and Health* 15, 147-152.

Bruner, J., Jolly, A. and Sylva, K. (1976) *Play: Its Role in Development and Evolution.* Harmondsworth, Penguin Education.

Bryman, A. (1988) *Quantity and Quality in Social Research.* London, Unwin Hyman.

Buckingham, D. (1994) Television and the definition of childhood. In Mayall, B. Ed. *Children's Childhoods: Observed and Experienced.* London, Falmer Press.

Bury, M.R. (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness* 4, 2, 167-182.

Callery, P. (1995) *An investigation into the role of parents in the care of hospitalised children.* Unpublished PhD Thesis, University of Liverpool.

Carnevale, F.A. (1997) The experience of critically ill children: Narratives of unmaking. *Intensive and Critical Care Nursing* 13, 1, 49-52.

Carnevale, F.A., MacDonald, M.E., Bluebond Langer, M. and McKeever, P. (2008) Using participant observation in pediatric health care settings: Ethical challenges and solutions. *Journal of Child Health Care* 12, 1, 18-32.

Carney, T., Murphy, S., McClure, J., Bishop, E., Kerr, C., Parker, J., Scott, F., Shields, C. and Wilson, L. (2003) Children's views of hospitalization: An exploratory study of data collection. *Journal of Child Health Care* 7, 1, 27-40.

Carter, B. (1998) Children- Silent consumers of health care. *Journal of Child Health Care* 2, 2, 57.

Carter, B., Lambrenos, K. and Thursfield, J. (2002) A pain workshop: An approach to eliciting the views of young people with chronic pain. *Journal of Clinical Nursing* 11, 6, 753-762.

Carter, B. (2004) Pain narratives and narrative practitioners: A way of working "in-relation" with children experiencing pain. *Journal of Nursing Management* 12, 3, 210-216.

Carter, B. (2005) "They've got to be as good as mum and dad": Children with complex needs and their siblings' perceptions of a Diana community nursing service. *Clinical Effectiveness in Nursing* 9, 49-61.

Carter, B. (2009) Tick box for child? The ethical positioning of children as vulnerable, researchers as barbarians and reviewers as overly cautious. *International Journal of Nursing Studies* 46, 6, 858-864.

Carter, B., Marshall, M. and Sanders, C. (2009) An exquisite knowing of children. In Locsin, R.C. and Purnell, M.J. Eds *A Contemporary Nursing Process. The (Un) Bearable Weight of Knowing in Nursing.* New York, Springer.

Carter, B. (In press) Researching children and young people: Exploring the ethical territory. In Brykczynska, G. and Simons, J. Eds. *Ethical and Philosophical Aspects of Nursing Children.* London, Wiley Blackwell.

Children Act (1989) London, HMSO.

Christensen, P., James, A. and Jenks, C. (2000) Home and movement: Children constructing family time. In Holloway, S. and Valentine, G. Eds. *Children's Geographies: Playing, Living, Learning.* London, Routledge.

Christensen, P. (2004) Children's participation in ethnographic research: Issues of power and representation. *Children and Society* 18, 165-176.

Clarke, K., Craig, G. and Glendinning, C. (1993) *Children Come First?* Barnados.

Clift, L., Dampier, S. and Timmons, S. (2007) Adolescents' experiences of emergency admissions to children's wards. *Journal of Child Health Care* 11, 3, 195-207.

Coad, J. and Evans, R. (2008) Reflections on practical approaches to involving children and young people in the data analysis process. *Children and Society* 22, 1, 41-52.

Cocks, A.J. (2006) The ethical maze: Finding an inclusive path towards gaining children's agreement to research participation. *Childhood* 13, 2, 247-266.

Corner, J. (1991) In search of more complete answers to research questions. Quantitative versus qualitative research methods: Is there a way forward? *Journal of Advanced Nursing* 16, 718-727.

Corsaro, W. (1981) Entering the child's world – Research strategies for field entry and data collection in a pre-school setting. In Green, J. and Wallat, C. Eds. *Ethnography and Language in Education Settings.* Norwood, Ablex Publishing.

Coyne, I. (2003) *A grounded theory of disrupted lives: Children, parents' and nurses in the children's ward.* Unpublished PhD Thesis, University of London.

Coyne, I. (2006) Consultation with children in hospital: Children, parents' and nurses' perspectives. *Journal of Clinical Nursing* 15, 61-71.

Coyne, I. (2007) Disruption of parent participation: Nurses' strategies to manage parents on children's wards. *Journal of Clinical Nursing* 17, 3150-3158.

Crisp, J., Ungerer, J. and Goodnow, J. (1996) The impact of experience on children's understanding of illness. *Journal of Pediatric Psychology* 21,1, 57-72.

Darbyshire, P. (1992) *Parenting in public: A study of the experiences of parents who live-in with their hospitalised child, and of their relationships with paediatric nurses.* Unpublished PhD Thesis. University of Edinburgh.

Darbyshire, P. (1994) *Living with a Sick Child in Hospital. The Experiences of Parents and Nurses.* London, Chapman and Hall.

Davis, J.M. (1998) Understanding the meanings of children: A reflexive process. *Children and Society* 12, 325-335.

Davis, J., Watson, N. and Cunningham-Burley, S. (2000) Learning the lives of disabled children. Developing a reflexive approach. In Christensen, P. and James, A. Eds. *Research with Children. Perspectives and Practices.* London, Falmer Press.

Denzin, N.K. and Lincoln, Y.S. (1994) *Handbook of Qualitative Research.* Thousand Oaks, CA, Sage.

Department of Health (1991) *The Welfare of Children and Young People in Hospital.* London, HMSO.

Department of Health (1996) *The Patient's Charter: Services for Children and Young People.* London, HMSO.

Department of Health (1997) The New NHS: Modern, Dependable. London, Stationery Office.

Department of Health (2000) *The NHS Plan: A Plan for Investment-A Plan for Reform.* London, The Stationery Office.

Department of Health (2002) *Listening, Hearing and Responding. Department of Health Action Plan: Core Principles for the Involvement of Children and Young People.* London, Department of Health.

Department of Health (2003) *Getting the Right Start: National Service Framework for Children. Standards for Hospital Services.* London, Department of Health, Department of Education and Skills.

Department of Health (2004) *National Standards Framework for Children, Young People and Maternity Services: Core Standards.* London, Department of Health, Department of Education and Skills.

Department of Health (2006) *Our Health, Our Care, Our Say: A New Direction for Community Services.* London, Department of Health, Department of Education and Skills.

Department of Health (2009) The NHS Constitution. The NHS belongs to us All. London, Department of Health.

Dixon-Woods, M., Young, B. and Heney, D. (1999) Partnerships with children. *British Medical Journal* 319, 778-780.

Docherty, S. and Sandelowski, M. (1999) Focus on qualitative methods. Interviewing children. *Research in Nursing and Health* 22, 2, 177-185.

Doorbar, P. (1995) *Children's Views of Health care in Portsmouth and South East Hampshire.* PDA and Portsmouth and South East Hampshire Health Authority.

DuBois, B. (1983) Passionate scholarship: Notes on values, knowing and method in feminist social science. In Bowles, G. and Klein, R. Eds. *Theories of Women's Studies* London, RKP.

Dunn, J. (1988) *The Beginnings of Social Understanding.* Oxford, Blackwell.

DuPlessis Van Breda, A. (2001) Resilience theory: A literature review. South African Military Health Service: Pretoria. Available from: http://www.vanbreda.org/adrian/resilience/resilience7.pdf.} [Accessed 09 December 2008].

Earle, R.J., Rennick, J.E., Carnevale, F.O. and Davis, G.M. (2006) "It's okay, it helps me breathe": The experiences of home ventilation from a child's perspective. *Journal of Child Health Care* 10, 4, 270-282.

Earvolino-Ramirez, M. (2007) Resilience: A concept analysis. *Nursing Forum* 42, 2, 73-82.

Eklund, P.G. and Sivberg, B. (2003) Adolescents lived experience of epilepsy. *Journal of Neuroscience Nursing* 35, 40-49.

Emond, R. (2006) Ethnographic research methods with children and young people. In Greene, S. and Hogan, D. Eds. *Researching Children's Experience. Approaches and Methods.* London, Sage.

Faux, S., Walsh, M. and Deatrick, J. (1988) Intensive interviewing with children. *Western Journal of Nursing Research* 10, 2, 180-194.

Faye, B. and Irurita, V.F. (2003) Balancing perspective: The response to feelings of being condemned with the hepatitis C virus. *Journal of Substance Use* 8, 2, 92-103.

Field, P. and Morse, J. (1985) *Nursing Research: The Application of Qualitative Approaches.* Beckenham, Kent, Croom Helm.

Fine, G.A. and Sandstrom, K.L. (1988) *Knowing Children: Participant Observation with Minors.* Newbury Park, Sage.

Fivush, R. and Hamond, N. (1990) Autobiographical memory across the pre-school years. Towards reconceptualising childhood amnesia. In Fivush, R. and Hudson, J. Eds. *Knowing and Remembering in Young Children. Emory Symposia in Cognition: Vol. 3* New York, Cambridge University Press.

Fivush, R., Hamond, N., Harsch, N., Singer, N. and Wolf, A. (1991) Content and consistency in young children's autobiographical recall. *Discourse Processes* 14, 373-388.

Fivush, R. (1993) Developmental perspectives on autobiographical recall. In Goodman G. and Bottoms, B. Eds. *Child Victims, Child Witnesses: Understanding and Improving Testimony.* New York, Guildford Press.

Flavell, J. (1992) Cognitive development: Past, present and future. *Developmental Psychology* 28, 6, 988-1005.

Fleitas, J.D. (1997) To tell you the truth: Children reflect on hospital care. *Issues in Comprehensive Pediatric Nursing* 20, 195-206.

Forsner, M., Jansson, L. and Sorlie, V. (2005a) The experience of being ill as narrated by hospitalised children aged 7-10 years with short-term illness. *Journal of Child Health Care* 9, 2, 153-165.

Forsner, M., Jansson, L. and Sorlie, V. (2005b) Being ill as narrated by children aged 11-18 years. *Journal of Child Health Care* 9, 4, 314-323.

Gallacher, L. and Gallagher, M. (2005) Participatory methods in research with children: A critique. In *Emerging Issues in the Geography of Children and Youth Conference.* Brunel University, 23rd June 2005.

Garth, B. and Aroni, R. (2003) "I value what you have to say". Seeking the perspective of children with a disability, not just their parents. *Disability and Society* 18, 5, 561-576.

Geertz, C. (1974) *The Interpretation of Cultures.* New York, Basic Books.

Gibson, F., Richardson, A., Hey, S., Horstman, M. and O'Leary, C. (2005) *Listening to Children and Young People with Cancer. Final report submitted to Macmillan Cancer Relief.* London, King's College London.

Gibson, F. and Twycross, A. (2007) Children's participation in research: A position statement on behalf of the Royal College of Nursing's Research in Child Health (RiCH) and Children's and Young People's Rights and Ethics Group. *Paediatric Nursing* 19, 4, 14-22.

Gibson, F. and Twycross, A. (2008) Editorial: Getting it right for children and young people's health care services. *Journal of Clinical Nursing* 17, 3081-3082.

Gilbert, N. (2008) *Researching Social Life.* Third edition. London, Sage.

Giske, T. and Artinian, B. (2008) Patterns of "balancing between hope and despair" in the diagnostic phase: A grounded theory study of patients on a gastroenterology ward. *Journal of Advanced Nursing* 62, 1, 22-31.

Glaser, B. (1978) *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory.* Mill Valley, California, The Sociology Press.

Glasper, E. and Powell, C. (1996) The challenge of the Children's Charter: Rhetoric vs reality. *British Journal of Nursing* 5, 1, 26-29.

Greene, S. and Hogan, D. (2006) *Researching Children's Experience. Approaches and Methods.* London, Sage.

Grieg, A. and Taylor, J. (1999) *Doing Research with Children.* London, Sage.

Guba, E.G. (1981) Criteria for the assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology Journal* 29, 2, 75-91.

Guba, E.G. and Lincoln, Y.S. (1994) Competing paradigms in qualitative research. In Denzin N.K. and Lincoln Y.S. Eds *Handbook of Qualitative Research.* Thousand Oaks, CA, Sage.

Gusella, J.L., Ward, A. and Butler, G.S. (1998) The experience of hospitalised children: How well do we meet their developmental needs? *Children's Health Care* 27, 131-145.

Hall, D. and Stacey, M. (1979) *Beyond Separation: Further Studies of Children in Hospital.* London, Routledge.

Hall, J. and Stevens, P. (1991) Rigor in feminist research. *Advances in Nursing Science* 13, 3, 16-29.

Hammersley, M. and Atkinson, P. (1995) *Ethnography. Principles in Practice.* London, Routledge.

Hammersley, M. (1998) *Reading Ethnographic Research.* London, Longman.

Hammersley, M. and Atkinson, P. (2002) *Ethnography. Principles in Practice.* Second Edition. London, Routledge.

Harden, J., Scott, S., Backett-Milburn, K. and Jackson, S. (2000) Can't talk, won't talk: Methodological issues in researching children. *Sociological Research Online* [Internet], 5. Available from: {http: //www.socresonline.org.uk/5/2/harden.html}. [Accessed 17 March 2009].

Hardman, C. (1973) "Can there be an anthropology of children?" *Journal of the Anthropology Society of Oxford* 4, 1, 85-99.

Hart, C. and Chesson, R. (1998) Children as consumers. *British Medical Journal* 346, 1600-1603.

Hatch, J. (1995) *Qualitative Research in Early Childhood Settings.* CT and London, Praeger, Westport.

Hertz, R. (1997) *Reflexivity and Voice.* Thousand Oaks CA, Sage.

Hill, M., Laybourn, A. and Borland, M. (1996) Engaging with primary-aged children about their emotions and well-being: Methodological considerations. *Children and Society* 10, 129-144.

Hill, M. (1997) Participatory research with children, *Child and Family Social Work* 2, 171–183.

Hilton, A. (1987) The ethnographic perspective. *Research Awareness Open Learning Programme Module 7.* London, South Bank Polytechnic Open Learning Centre.

Hinds, P.S., Hockenberry-Eaton, M., Gilger, E., Kline, N., Burleson, C., Bottomley, S. and Quargnenti, A. (1999) Comparing patient, parents and staff descriptions of fatigue in paediatric oncology patients. *Cancer Nursing* 22, 4, 277-289.

Hodges, K. (1993) Structured interviews for assessing children. *Journal of Child Psychology and Psychiatry* 34, 1, 49-68.

Hogan, D. (2006) Researching "the child" in developmental psychology. In Greene, S. and Hogan, D. Eds. *Researching Children's Experience. Approaches and Methods.* London, Sage.

Holyoake, D.D. (1999) Who's the boss? Children's perceptions of hospital hierarchy. *Paediatric Nursing* 11, 5, 33-36.

Homer, C.J., Marino, B., Cleary, P.D., Alpert, H.R., Smith, B., Crowley Granser, C.M., Brustowicz, R.M. and Goldmann, D.A. (1999) Quality of care at a children's hospital: The parents' perspective. *Archives of Pediatrics and Adolescent Medicine* 153, 11, 1123-1129.

Horne, S. (1999) Phenomenology: Understanding the life experience of long-term ventilated adolescents. *Paediatric Nursing* 11, 37-39.

Horstman, M. and Bradding, A. (2002) Helping children speak up in the health service. *European Journal of Oncology Nursing* 6, 2, 75-84.

Horstman, M., Aldiss, S., Richardson, A. and Gibson, F. (2008) Methodological issues when using the draw and write technique with children aged 6 to 12 years. *Qualitative Health Research* 18, 7, 1001-1011.

Ireland, L. and Holloway, I. (1996) Qualitative health research with children. *Children and Society* 10, 155-164.

Irwin, L.G. and Johnson, J. (2005) Interviewing young children: Explicating our practices and dilemmas. *Qualitative Health Research* 15, 6, 821-831.

Jackson, S. and Scott, S. (2000) Childhood. In Payne, G. Ed. *Social Divisions.* London, Macmillan.

James, A. and Prout, A. (1990) Re-presenting childhood: Time and transition in the study of childhood. In James, A. and Prout, A. Eds. *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood.* London, Falmer Press.

James, A. (1995) On being a child: The self, the group and the category. In Cohen A. and Rapport N. Eds. *Questions of Consciousness.* London, Routledge.

James, A. and Prout, A. (1997) *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood.* London, Falmer Press.

James, A. (1998) Children, Health and Illness. In Field, D. and Taylor, S. Eds. *Sociological Perspectives on Health, Illness and Health Care.* London, Blackwell Science Ltd.

James, A., Jenks, C. and Prout, A. (1998) *Theorizing Childhood.* Cambridge, Polity Press.

James, A. (2001) Ethnography in the study of children and childhood. In Atkinson, P.A., Delamont, S., Coffey, A., Lofland, J. and Lofland, L. Eds. *Handbook of Ethnography.* London, Sage.

James, A., Jenks, C. and Prout, A. (2001) The Presociological Child. In James, A., Jenks, C. and Prout, A. Eds. *Theorizing Childhood.* Cambridge, Polity Press.

James, A. and James, A. (2008) *Key Concepts in Childhood Studies.* London, Sage.

Jenks, C. (1996) *Childhood.* London, Routledge.

Kaplan, S., Busner, J., Chibnall, J. and Kang, G. (2001) Consumer satisfaction at a child and adolescent state psychiatric hospital. *Psychiatric Services* 52, 5, 202-206.

Kari, J.A., Donovan, C., Li, J. and Taylor, B. (1999) Teenagers in hospital: What do they want? *Nursing Standard* 24, 13, 49-51.

Kelly, B. (2005) "Chocolate ... makes you autism": Childhood identities. *Disability and Society* 20, 3, 261-275.

Kirby, P. and Bryson, S. (2002) *Measuring the Magic? Evaluating and Researching Young People's Participation in Public Decision Making.* London, Carnegie Young People Initiative.

Kirk, S. (2007) Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *International Journal of Nursing Studies* 44, 1250-1260.

Kleinman, A. (1988) *The Illness Narratives: Suffering, Healing and the Human Condition.* New York, Basic Books.

Knafl, K.A., Cavallari, K.A. and Dixon, D.M. (1988) *Pediatric Hospitalization: Family and Nurse Perspectives.* Illinois, Scott, Foresman and Co.

Kortesluoma, R.L., Hentinen, M. and Nikkonen, M. (2003) Conducting a qualitative child interview: Methodological considerations. *Methodological Issues in Nursing Research* 42, 5, 434-441.

Kortesluoma, R.L. and Nikkonen, M. (2006) "The most disgusting ever": Children's pain descriptions and views of the purpose of pain. *Journal of Child Health Care* 10, 3, 213-227.

Kralik, D. (1997) Engagement and detachment: Understanding patients' experiences with nursing. *Journal of Advanced Nursing* 26, 2, 399-407.

Laerke, A. (1998) By means of remembering. Notes on a fieldwork with English children. *Anthropology Today* 14, 3-7.

Lansdown, G. (1994) Children's Rights. In Mayall, B. Ed. *Children's Childhood Observed and Experienced.* London, The Falmer Press.

Lansdown, R. (1998) Listening to children: Have we gone too far (or not far enough)? *Journal of the Royal Society of Medicine* 91, 457-461.

Lansdown, G. (2000) Implementing children's rights and health. *Archive of Diseases in Childhood* 83, 286-288.

Laugharne, C. (1995) *Ethnography: Research method or philosophy?* 3, 2, 45-54.

Leininger, M. (1985) Ethnography and ethnonursing: Models and modes of qualitative data analysis. In Leininger, M. Ed. *Qualitative Research Methods in Nursing.* Orlando, F.L. Grune and Stratton Inc.

Levealahti, H., Tishelman, C. and Ohlen, J. (2007) Framing the onset of lung cancer biographically: Narratives of continuity and disruption. *Psycho-Oncology* 16, 466-473.

Levy, V. (1999) Maintaining equilibrium: A grounded theory study of the processes involved when women make informed choices during pregnancy. *Midwifery* 15, 109-119.

Lightfoot, J. and Sloper, P. (2003) Having a say in health: Involving children and young people with a chronic or physical disability in local health services development. *Children and Society* 17, 277-290.

Lindeke, L., Hauck, M. and Tanner, M. (2000) Practical issues in obtaining child assent for research. *Journal of Pediatric Nursing* 15, 2, 99-104.

Lindeke, L. and Johnson, L. (2006) Capturing children's voices for quality improvement. *The American Journal of Maternal/Child Nursing* 31, 5, 290-295.

Lindsay Waters, A. (2008) An ethnography of a children's renal unit: Experiences of children and young people with long-term renal illness. *Journal of Clinical Nursing* 17, 3103-3114.

Lofland, J. and Lofland, L. (1971) *Analysing Social Settings. A Guide to Qualitative Observation and Analysis.* Second Edition. California, Wadsworth Publishing Company.

Long, A. (1984) *Research into Health and Illness. Issues in Design, Analysis and Practice.* England, Gower Publishing Co. Ltd.

Lumeng, J.C., Warschausky, S.A., Nelson, V.S. and Augenstein, K. (2001) The quality of life of ventilator-assisted children. *Pediatric Rehabilitation* 4, 1, 21-27.

Mackenzie, A. (1994) Evaluating ethnography: Considerations for analysis. *Journal of Advanced Nursing* 19, 774-781.

Maggs-Rapport, F. (2001) "Best research practice": In pursuit of methodological rigour. *Journal of Advanced Nursing* 35, 3, 373-383.

Mahon, A. and Higgins, J. (1995) *"A Life of Our Own ..." Young Carers: An Evaluation of Three RHA Funded Projects in Merseyside Health Services.* Management Unit, University of Manchester.

Mahon, A., Glendinning, C., Clarke, K. and Craig, G. (1996) Researching children: Methods and ethics. *Children and Society* 10, 145-154.

Marshall, J. (1986) Exploiting the experience of women managers towards rigour in qualitative methods. In Wilkinson, S. Ed. *Feminist Social Psychology: Developing Theory and Practise.* Milton Keynes, Open University Press.

Mayall, B. (1994) Introduction. In Mayall, B. Ed. *Children's Childhoods Observed and Experienced.* London, Falmer Press.

Mayall, B. (1995) The changing context of childhood: Children's perspectives on health care resources including services. In Botting, B. Ed. *The Health of our Children.* London, HMSO.

Mayall, B. (1996) *Children, Health and the Social Order.* Buckingham, Open University Press.

Mayall, B., Bendelow, G. and Barker, S. (1997) *Children's Health in Primary Schools.* London, Falmer.

Mayall, B. (2000) Conversations with children: Working with generational issues. In Christensen, P. and James, A. Eds. *Research with Children. Perspectives and Practices.* London, Falmer Press.

Mays, N. and Pope, C. Assessing quality in qualitative research. (2000) *BMJ* 320, 50-52.

McCormick, K.M. (2002) A concept analysis of uncertainty in illness. *Image: Journal of Nursing Scholarship* 34, 2, 127-131.

McGurk, H. and Glachan, M. (1988) Children's conversations with adults. *Children and Society* 2, 20-34.

McNeish, D. and Newman, T. (2002) Involving children and young people in decision making. In McNeish, D., Newman, T., and Roberts, H. Eds. *What Works for Children?* Buckingham, Open University Press.

Medical Research Council (2004) *MRC Ethics Guide. Medical Research Involving Children.* London, MRC.

Miller, S. (2000) Researching children: Issues arising from a phenomenological study with children who have diabetes mellitus. *Journal of Advanced Nursing* 31, 5, 1228-1234.

Mitchell, K. (1984) Protecting children's rights during research. *Pediatric Nursing* 10, 1, 9-10.

Moore, M., Beazley, S. and Maelzer, J. (1998) *Researching Disability Issues.* Open University Press.

Morrow, V. and Richards, M. (1996) The ethics of social research on children: An overview. *Children & Society* 10, 90-105.

Morse, J. and Field, P. (1996) *Nursing Research. The Application of Qualitative Approaches.* London, Chapman & Hall.

Moules, T. (2009) "They wouldn't know how it feels …": Characteristics of quality care from young people's perspectives: A participatory research project. *Journal of Child Health Care* 13, 4, 322-332.

National Children's Bureau (2003) *Guidelines for Research.* London, NCB.

Noyes, J. (2000) Enabling young "ventilator-dependent" people to express their views and experiences of their care in hospital. *Journal of Advanced Nursing* 31, 5, 1206-1215.

Oakley, A. (1994) Women and Children First and Last: Parallels and Differences between Children's and Women's Studies. In Mayall, B. Ed. *Children's Childhood Observed and Experienced.* London, The Falmer Press.

Parse, R. (1981) *Man-Living-Health: A Theory of Nursing.* New York, John Wiley and Sons.

Payne, L. (2009) Twenty years on: The implementation of the UN Convention on the Rights of the Child in the United Kingdom. *Children and Society* 23, 149-155.

Pelander, T. and Leino-Kilpi, H. (2004) Quality in pediatric nursing care: Children's expectations. *Issues in Comprehensive Pediatric Nursing* 27, 139-151.

Pellatt, G. (2003) Ethnography and reflexivity: Emotions and feelings in fieldwork. *Nurse Researcher* 10, 3, 28-37.

Peshkin, A. (1988) In search of subjectivity. One's own. *Educational Research* 17, 17-22.

Piaget, J. (1952) *The Origins of Intelligence in Children.* Translated from French by Worden, M. New York, Harcourt, Brace and World.

Piaget, J. (1957) *Logic and Psychology.* New York, Basic Books.

Piercy, H. and Hargate, M. (2004) Social research on the under-16s: A consideration of the issues from a UK perspective. *Journal of Child Health Care* 8, 4, 253-263.

Polit, D. and Hungler, B. (1991) *Nursing Research. Principles and Methods.* Fourth Edition. Philadelphia, J.B. Lippincott.

Polkki, T., Pietila, A.M. and Rissanen, L. (1999) Pain in children: Qualitative research of Finnish school-aged children's experiences of pain in hospital. *International Journal of Nursing Practice* 5, 1, 21-28.

Pretzlik, U. (1995) Observational methods and strategies. *Nurse Researcher* 2, 107-115.

Punch, S. (2002) Research with children-The same or different from research with adults? *Childhood* 9, 3, 321-341.

Qvortrup, J. (1994) Childhood Matters: An Introduction. In Qvortrup, J., Bardy M., Sgritta, C. and Wintersberger, H. Eds. *Childhood Matters: Social Theory, Practice and Politics.* Aldershot, Avebury.

Rabibee, P., Sloper, P. and Beresford, B. (2005) Doing research with children and young people who do not use speech for communication. *Children and Society* 19, 5, 385-396.

Randall, D., Brook, G. and Stammers, P. (2008) How to make good children's nurses: Children's views. *Paediatric Nursing* 20, 5, 22-25.

Rhee, H., Wenzel, J. and Stevens, R.H. (2007) Adolescents' psychosocial experiences living with asthma: A focus group study. *Journal of Pediatric Health Care* 21, 99-107.

Rich, J. (1968) *Interviewing Children and Adolescents.* New York, Macmillan.

Richman, J. and Skidmore, D. (2000) Health implications of modern childhood. *Journal of Child Health Care* 4, 3, 106-110.

Ritala-Koskinen, A. (1994) Children and the Constitution of Close Relationships: How to Find Out the Child's Point of View. In *Childhood and Parenthood Conference.* University of London.

Roach, S. (1984) *Caring: The Human Mode of Being.* Toronto, University of Toronto.

Robertson, M.H. and Boyle, J.S. (1984) Ethnography: Contributions to nursing research. *Journal of Advanced Nursing* 9, 43-49.

Robinson, C. and Kellett, M. (2004) Power. In Fraser, S., Lewis, V., Ding, S., Kellett, M. and Robinson, C. Eds. *Doing Research with Children and Young People.* London, Sage.

Royal College of Nursing (1999) *Ouch! Sort It Out. Children's Experiences of Pain.* London, RCN.

Royal College of Nursing (2009) *Research Ethics. RCN Guidance for Nurses.* London, RCN.

Royal College of Paediatrics and Child Health: Ethics Advisory Committee (2000) Guidelines for the ethical conduct of medical research involving children. *Archives of Diseases in Childhood* 82, 177-182.

Runeson, I., Enskar, K., Elander, G. and Hermeren, G. (2001) Professionals' perceptions of children's participation in decision making in health care. *Journal of Clinical Nursing* 10, 70-78.

Ryan-Nicholls, K.D. and Will, C.I. (2009) Rigour in qualitative research: Mechanisms for control. *Nurse Researcher* 16, 3, 70-86.

Rydstrom, I., Dalheim Englund, A.C. and Sandman, P.O. (1999) Being a child with asthma. *Pediatric Nursing* 25, 6, 589-596.

Sands, A. (1996) *Perceptions of family-centred care for children in hospital.* Unpublished Masters Dissertation, University of Sheffield.

Sartain, S.A., Clarke, C. and Heyman, R. (2000) Hearing the voices of children with chronic illness. *Journal of Advanced Nursing* 32, 4, 913-921.

Sartain, S.A., Maxwell, M.J., Todd, P.J., Haycox, A.R. and Bundred, P.E. (2001) Users' views on hospital and home care for acute illness in childhood. *Health and Social Care in the Community* 9, 2, 108-117.

Savage, J. (2006) Ethnographic evidence: The value of applied ethnography in healthcare. *Journal of Research in Nursing* 11, 5, 383-393.

Schaffer, P., Vaughn, G., Kenner, C., Donohue, F. and Longo, A. (2000) Revision a parent satisfaction survey based on the parent perspective. *Journal of Pediatric Nursing* 15, 6, 373-377.

Schatzman, L. and Strauss, A. (1973) *Field Research: Strategies for a Natural Sociology*. Englewood Cliffs, New Jersey, Prentice Hall.

Schmidt, C., Bernaix, L., Koski, A.m Weese, J. Chiappetta, M. and Sandrik, K. (2007) Hospitalized children's perceptions of nurses and nurse behaviours. *MCN The American Journal of Maternal/Child Nursing* 32, 6, 336-342.

Shakespeare, T. and Watson, N. (1998) Theoretical perspectives on research with disabled children. In Robinson, C. and Stalker, K. Eds. *Growing Up with a Disability*. London, Jessica Kingsley Publishers Ltd.

Sigelman, C., Maddock, A., Epstein, J. and Carpenter, W. (1993) Age differences in understandings of disease causality-Aids, colds and cancer. *Child Development* 64, 1, 272-284.

Silverman, D. (2005) *Doing Qualitative Research*. Second Edition. London, Sage.

Sloper, P. and Lightfoot, J. (2003) Involving disabled and chronically ill children and young people in health service development. *Child: Care, Health and Development* 29, 15-20.

Stacey, M. (1976) The health service consumer: A sociological misconception. In Stacey, M. Ed. *The Sociology of the National Health Service. Monograph 22*. Staffordshire, University of Keele.

Steward, M. and Steward, D. (1996) Interviewing young children about body touch and handling. *Monographs of the Society for Research in Child Development* 61 (4, Serial No. 248).

Swallow, V. (2008) An exploration of mothers' and fathers' views of their identities in chronic kidney disease management: Parents as students? *Journal of Clinical Nursing* 17, 3177-3186.

The Guardian (2009) Editorial: Children not seen, nor heard. The Guardian, 21 April 2009.

Thompson, M.L. (1994) Information-seeking, coping and anxiety in school-age children anticipating surgery. *Children's Health Care* 23, 87-97.

Thulesius, H., Hakansson, A, and Petersson, K. (2003) Balancing: A basic process in end-of-life cancer care. *Qualitative Health Research* 13, 10, 1353-1377.

Twinn, S. (2006) Balancing uncertainty and acceptance: Understanding Chinese women's responses to an abnormal cervical smear result. *Journal of Clinical Nursing* 15, 1140-1148.

Twycross, A., Gibson, F. and Coad, J. (2008) Guidance on seeking agreement to participate in research from young children. *Paediatric Nursing* 20, 6, 14-22.

Tymchuk, A. (1992) Assent processes. In Stanley, B. and Sieber, J. Eds. *Social Research on Children and Adolescents: Ethical Issues.* London, Sage.

United Nations Convention of the Rights on the Child (1989): Adopted by the General Assembly of the United Nations on 20th November 1989. London, HMSO.

UNICEF (2009) *The State of the World's Children.* New York, UNICEF.

Valentine, G. (1999) "Being seen and heard?" The ethical complexities of working with children and young people at home and at school. *Ethics, Place and Environment* 2, 2, 141-155.

Wainwright, S. (1994) Analysing data using grounded theory. *Nurse Researcher* 1, 3, 43-46.

Waksler, F. C. (1986) Studying children: Phenomenological insights. *Human Studies* 9, 1, 71-82.

Waksler, F.C. (1991) *Studying the Social Worlds of Children: Sociological Readings.* London, Falmer Press.

Walsh, M. (1983) *The experience of asthma in childhood.* Unpublished Doctoral Dissertation, University of Illinois.

Waltz, C., Strickland, O. and Lenz, E. (1984) *Measurement in Nursing Research.* Philadelphia, F.A. Davis.

Ward, L. (1997) *Seen and Heard. Involving Disabled Children and Young People in Research and Development Projects.* Joseph Rowntree Foundation.

Webb, C. (1993) Feminist research: Definitions, methodology, methods and evaluation. *Journal of Advanced Nursing*, 18, 416-423.

Wheeler, R. (2006) Gillick or Fraser? A plea for consistency over competence in children. *BMJ* 332, 807.

While, A.E. and Mullen, J. (2004) Living with sickle cell disease: The perspective of young people. *British Journal of Nursing* 13, 6, 320-325.

Whittemore, R. (2000) Consequences of not "knowing the patient". *Clinical Nurse Specialist* 14, 2, 75-81.

Whyte, D. (1997) *Explorations in Family Nursing.* London, Routledge.

Williams, S.J. (2000) Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness* 22, 1, 40-67.

Wilson, B. and Crowe, M. (2008) Maintaining equilibrium: A theory of job satisfaction for community mental health nurses. *Journal of Psychiatric and Mental Health Nursing* 15, 10, 816-822.

Wise, B.V. (2002) In their own words: The lived experience of pediatric liver transplantation. *Qualitative Health Research* 12, 1, 74-90.

Woodgate, R.L. (2001) Adopting the qualitative paradigm to understanding children's perspectives of illness: Barrier or facilitator? *Journal of Pediatric Nursing* 16, 3, 149-161.

Woodhead, M. (1997) Psychology and the cultural construction of children's needs. In James, A. and Prout, A. Eds. *Constructing and Reconstructing Childhood.* London, Falmer Press.

Woods, L., Priest, H. and Roberts, P. (2002) An overview of three different approaches to the interpretation of qualitative data. Part 2: Practical illustrations. *Nurse Researcher* 10, 1, 43-51.

Wyse, D. and Hawtin, A. (2000) *Children: A Multi-Professional Practice.* London, Hodder Headline Group.

Yarrow, L. (1960) Interviewing children. In Mussen, P. Ed. *Handbook of Research Methods in Child Development.* New York, John Wiley.

APPENDICES

APPENDIX 1:

Summary of key ethical principles relating to research involving children: "MRC Ethics Guide: Medical Research involving Children" (2004)

Children require special protection because they are less likely to be able to express their needs or defend their interests-they may not have the capacity to give consent.

Research should only include children where the relevant knowledge cannot be obtained by research in adults.

The purpose of the research is to obtain knowledge relevant to the health, wellbeing or healthcare needs of children.

Researchers can only involve competent children if they have obtained their informed consent beforehand.

A child's refusal to participate or continue in research should always be respected.

If a child becomes upset by a procedure, researchers must accept this as valid refusal.

Researchers should involve parents/guardians in the decision to participate wherever possible, and in all cases where the child is not yet competent.

Researchers should attempt to avoid any pressures that might lead the child to volunteer for research or that might lead parents to volunteer their children in the expectation of direct benefit (whether therapeutic or financial).

Research involves partnership with the child and/or family who should be kept informed and consent to separate stages of the project. Obtaining consent is a continuing process, rather than a one-off occurrence. Children and their families are likely to appreciate some recognition of their role in this partnership, such as a certificate of participation.

Researchers must take account of the cumulative medical, emotional, social and psychological consequences of the child being involved in research. Children with certain conditions may be exposed to a sequence of research projects. It is advisable to consider the risks of a particular research procedure in the context of the child's overall involvement in projects by different researchers.

[Summary of key ethical principles relating to research involving children: "MRC Ethics Guide: Medical Research involving Children" (2004)]

APPENDIX 2:
Children's information sheet (5-8 years)

CHILDREN'S INFORMATION SHEET

Hello, my name is Maria. I am a nurse. One of my jobs is to look after children when they are poorly.

I would like to find out what children think about being in hospital. This means that there are no right or wrong answers.

If you don't mind I would like to ask you some questions about what it feels like to be in hospital.

All the things that children tell me will help the nurses to learn about what poorly children would like when they are in hospital to help them feel better.

I have had a talk with your family to ask them if it is OK to ask you some questions. I would like you to tell me if it is OK too!

You don't have to help if you don't want to - that's OK!

You can have some time to think about whether you want me to ask you some questions before you decide. You might want to talk about this with your family and friends.

If you decide that you want to help and then change your mind, that is OK. Or if you don't feel like answering any of my questions, that is OK too.

If you like, before I ask you any questions we can talk about how you will let me know that you don't want to answer a question. We can also talk about how you will let me know that you want me to stop asking questions if you want to play for a while instead.

If you decide to help me with my project I will ask you if I can tape the things you tell me. If you don't mind me doing this I will show you how the tape recorder works. This means that you can hold the tape recorder and stop it whenever you want to. If you don't want me to tape what you tell me, that is OK too!

If you want your family to know what we have talked about then we will tell them. If you don't, then we won't. I will talk to your family about this so that they know too. I won't tell any of the nurses or doctors what you have told me unless you ask me to.

I will keep everything that you tell me in a safe place so that nobody else will know who has said it. I will be the only person who will know what you have told me. If you don't mind I will use the things you have told me in a project I am writing. This means that my teachers and maybe a few other people might read part of what you have said. If you like, we can choose a pretend name together so the people who read my project won't know that you have answered my questions.

When I have finished my project if you want me to, I can send you a special report that lets you know the things the children have told me.

APPENDIX 3:
Children's information sheet (9-12 years)

CHILDREN'S INFORMATION SHEET

ABOUT THE PROJECT

This project wants to find out what children think about being in hospital and which people children want to spend time with them while they are there. This includes people who are important to children, such as mum, dad, brothers, sisters and cousins. The project will find out which of these important people children would like to help look after them along with the nurses while they are in hospital. Finding out the answers to these questions will help nurses to learn about which people children feel are important to them when they are in hospital, as well as what being in hospital is like.

ABOUT THE PEOPLE CARRYING OUT THE PROJECT

My name is Maria Hargate. I am working on the project. My job is to work with children like you on the project and then to tell nurses and other people who look after children in hospital the things I have found out. I also work some of the time as a nurse.

WHY ME?

I would like to talk to children who are aged between 5 to 16 years and are being looked after in one of the wards at Sheffield Children's Hospital. That is why you and your parents have been given this form.

WHAT HAPPENS FIRST?

Before you decide you can have some time to think about whether you want to take part. You might want to talk to your family and friends first to help you decide. I have had a talk with your parents already to ask them if it is OK for me to give you this information sheet. This is because the hospital has important rules which have to be followed when asking children if they would like to take part in projects.

WHAT WOULD HAPPEN IF I TOOK PART ?

First of all, I would come and see you while you are still in hospital. That is so you can ask more about the project and get to know me.

The project will involve me asking you some questions about what it is like to be in hospital. Before I begin we can talk about ways in which you can let me know that you want me to stop asking questions. We can also talk about how you can say that you don't want to answer any of the questions.

If you agree, I will tape the answers you give me. If you don't mind being taped I will give you the tape recorder to hold so that you can stop it recording whenever you want to. If you don't want to be taped that is OK.

The questions I ask you will last about an hour. We can do lots of different activities such as drawing to help you think and talk about what it is like being in hospital.

WILL ANYONE FIND OUT WHAT I HAVE TOLD YOU ?

Everything you tell me is private. Of course you can tell your family and friends about the project if you want to.

I will keep the information that you tell me in a safe place so that no-one else can see it. If you agree I will use the information that you have told me in the project. However, when I write the project, I won't use your name. This means that no-one will know what you have said.

WHAT IF I DON'T WANT TO TAKE PART ?

That's OK. Nobody will mind if you don't want to take part. If you do decide to take part and then change your mind, that's OK as well.

YES, I'D LIKE TO HELP WITH THE PROJECT

That's great! Before you begin to help I will give you a certificate to read and sign which will help you to be sure that you understand about the project.

AFTER THE PROJECT IS FINISHED

If you would like a special report once the project is finished that explains the information the children have told me, please let me know and I can send one on to you.

APPENDIX 4:
Young people's information sheet

YOUNG PEOPLE'S INFORMATION SHEET

FAMILY CENTRED CARE: CHILDREN'S PERSPECTIVES

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your friends and family. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

When a young person has an illness requiring admission to hospital, life can be considerably disrupted for both young people and their families. This research will explore young people's views on being in hospital and which family members they would like to be involved in their care. I hope that the study will provide information about how young people can best be supported during their time in hospital by parents and other family members.

Why have I been invited to take part?

I would like to talk to young people who are aged between 5 and 16 years and are patients on Ward xx at the xx Hospital.

Do I have to agree to take part?

It is up to you to decide whether or not to take part. If you do decide to agree to take part you will be given this information sheet to keep and be asked to sign an assent form. Before you take part in the study it is very important that you read the young people's information sheet in order to ensure that you understand what helping with the project means. I will be available at this time to give you any further information you need.

If you agree to take part you will be asked to sign an assent form. If you decide to take part you will be free to withdraw from the study at any time and will not have to give a reason. Deciding not to be involved in the study will not affect the standard of care you will receive.

Whilst I have been given permission by the xx Hospital to carry out this research I am not employed at the hospital. Therefore, I will not be involved in your clinical care in any way.

What will happen if I take part?

The first part of the research will involve the researcher observing everyday activities on the ward at the time you are in hospital. This will help the researcher to understand young people's experiences of being in hospital and will provide some examples of activities that the researcher could talk to you about. Talking to the researcher will last approximately 60 minutes. Time will be built into the interview to allow you to have a break if you become tired. You will be able to choose whether or not you want someone to be with you during the interview such as a parent, grandparent, sibling or friend. You will be interviewed only once.

When and where will the interviews take place?

The interview will take place on ward xx while you are still an inpatient on the ward. However, the interview will be carried out at a time close to your discharge home or when you feel well enough to talk about your experiences in hospital and are not in any pain or discomfort.

What other information will be collected in the study?

With your agreement we will obtain information about your treatment and hospital admission from the nursing records.

Will there be any effects on my treatment?

No, whether or not you participate in the study will not affect your treatment in any way.

Will the information obtained in the study be confidential?

Anything you say will be treated in confidence, no names will be mentioned in any reports of the study and care will be taken so that individual young people cannot be identified from details in reports of the results of the study.

Will anyone else be told about my participation in the study?

With your agreement, the nurses on the ward will be told that you are helping with the study. However, anything you say will be treated in confidence so the ward staff will not have access to any information you have given.

What will happen to the results of the research study?

A report of the project will be written for nurses and other health professionals who look after young people in hospital. A list of recommendations about the best ways in which people who are important to young people can be helped to look after them in hospital in the ways that young people view as being important will be drawn up. Both the report and the recommendations will be distributed widely.

What if I wish to complain about the way in which this study has been conducted?

If you have *any* cause to complain about *any* aspect of the way in which you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you. You are not compromised in any way because you have taken part in a research study.
If you do have any complaints or concerns you are able to contact the project supervisor:

xx. Tel: xx.

Or you can use the normal hospital complaints procedure and contact the following person:

xx. Tel: xx.

Or you can use the formal University complaints procedure and contact :

xx. Tel: xx.

Contact for Further Information?

If you have any questions about the project please do not hesitate to contact me.

Maria Hargate

E mail address: xx.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW.

APPENDIX 5:
Parents' information sheet: Preliminary phase observation

PARENT INFORMATION SHEET

FAMILY CENTRED CARE: CHILDREN'S PERSPECTIVES

You are being invited to consider allowing your child to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

When a child has an illness requiring admission to hospital, life can be considerably disrupted for both children and their families. This research will explore children's views on which family members they would like to be involved in their care during their time in hospital and what they would like them to do. I hope that the study will provide information about how children can best be supported during their time in hospital by parents and other family members.

Why has my child been chosen?

I would like to involve children who are patients on ward xx at the xx Hospital.

Do I have to agree for my child to take part?

It is up to you to decide whether or not I can ask your child to take part. If you do agree to your child taking part you will be given this information sheet to keep and be asked to sign a consent form. Before your child takes part in the study it is very important that they understand what helping with the project means. I will be available at this time to give you any further information either you or your child need.

If you and your child decide to take part you will be free to withdraw from the study at any time and will not have to give a reason. Deciding not to be involved with the study will not affect the standard of care either you or your child will receive.

Whilst I have been given permission by the xx Hospital to carry out this research I am not employed at the hospital. Therefore, I will not be involved in the clinical care of your child in any way.

What will happen to my child if he/she takes part?

The research will involve the researcher observing everyday activities on the ward at the time your child is in hospital. This will help the researcher to understand children's experiences of being in hospital. The sorts of things that will be observed are, for example, a nurse giving a medicine with a family member helping. Your child will be involved in the research by being a patient in the ward at the time these everyday activities are being observed.

What other information will be collected in the study?

No other information will be collected about your child.

Will there be any effects on my child's treatment?

No, whether or not your child participates in the study their treatment will not be affected in any way.

Will the information obtained in the study be confidential?

All the activities that are observed whilst your child is involved in the study will be treated in confidence.

Will anyone else be told about my child's participation in the study?

With your agreement, the nurses on the ward will be told that your child is helping with the study.

What will happen to the results of the research study?

A report of the project will be written for nurses and other health professionals who look after children in hospital. A list of recommendations about he best ways in which people who are important to children can be helped to look after them in hospital in the ways that children view as being important will be drawn up. Both the report and the recommendations will be distributed widely.

What if I wish to complain about the way in which this study has been conducted?

If you have *any* cause to complain about *any* aspect of the way in which you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you. You are not compromised in any way because you have taken part in a research study.

If you do have any complaints or concerns you are able to contact the project supervisor:

xx. Tel: xx.

Or you can use the normal hospital complaints procedure and contact the following person :

xx. Tel: xx.

Or you can use the formal University complaints procedure and contact :

xx. Tel: xx.

Contact for Further Information?
If you have any questions about the project please do not hesitate to contact me.

Tel: xx.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW.

APPENDIX 6:
Parents' information sheet: Full study

PARENT INFORMATION SHEET

FAMILY CENTRED CARE: CHILDREN'S PERSPECTIVES

You are being invited to consider allowing your child to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

When a child has an illness requiring admission to hospital, life can be considerably disrupted for both children and their families. This research will explore children and young people's views on being in hospital and which family members they would like to be involved in their care. I hope that the study will provide information about how children and young people can best be supported during their time in hospital by parents and other family members.

Why has my child been chosen?

I would like to talk to children who are aged between 5 and 16 years and are patients on Ward xx at the xx Hospital.

Do I have to agree for my child to take part?

It is up to you to decide whether or not I can ask your child to take part. If you do decide to agree to your child taking part you will be given this information sheet to keep and be asked to sign a consent form. Before your child takes part in the study it is very important that they read, or have read to them, a specially designed information sheet in order to ensure that they understand what helping with the project means. I will be available at this time to give you any further information either you or your child need.

If your child agrees to take part he/she will be asked to sign a special assent form very similar to your own consent form. If you and your child decide to take part you will be free to withdraw from the study at any time and will not have to give a reason. Deciding not to be involved in the study will not affect the standard of care either you or your child will receive.

Whilst I have been given permission by the xx Hospital to carry out this research I am not employed at the hospital. Therefore, I will not be involved in the clinical care of your child in any way.

What will happen to my child if he/she takes part?

The first part of the research will involve the researcher observing everyday activities on the ward at the time your child is in hospital. This will help the researcher to understand children's experiences of being in hospital and will provide some examples of activities that the researcher could talk to your child about, for example, a nurse giving a medicine with a family member helping. Using a range of activities including drawing; children will be encouraged to think about the people that are important to them when they are in hospital and the sorts of things these people can do to help make being in hospital better. This will last approximately 60 minutes. Time will be built into the interview to allow your child to rest or play for a short while if they become tired or bored. Your child will be able to choose whether or not they want someone to be with them during the interview such as a parent, grandparent or sibling. Your child will be interviewed only once.

When and where will the interviews take place?

The interview will take place on ward xx while your child is still an inpatient on the ward. However, the interview will be carried out at a time close to your child's discharge home or when they feel well enough to talk about their experiences in hospital and are not in any pain or discomfort.

What other information will be collected in the study?

With your agreement we will obtain information on your child's treatment and hospital admission from the nursing records.

Will there be any effects on my child's treatment?

No, whether or not your child participates in the study their treatment will not be affected in any way.

Will the information obtained in the study be confidential?

Anything either you or your child says will be treated in confidence, no names will be mentioned in any reports of the study and care will be taken so that individual children cannot be identified from details in reports of the results of the study.

Will anyone else be told about my child's participation in the study?

With your agreement, the nurses on the ward will be told that your child is helping with the study. However, anything either you or your child says will be treated in confidence so the ward staff will not have access to any information you or your child have given.

What will happen to the results of the research study?

A report of the project will be written for nurses and other health professionals who look after children in hospital. A list of recommendations about the best ways in which people who are important to children can be helped to look after them in hospital in the ways that children view as being important will be drawn up. Both the report and the recommendations will be distributed widely.

What if I wish to complain about the way in which this study has been conducted?

If you have *any* cause to complain about *any* aspect of the way in which you have been approached or treated during the course of this study, the normal National Health

Service complaints mechanisms are available to you. You are not compromised in any way because you have taken part in a research study.

If you do have any complaints or concerns you are able to contact the project supervisor:

Xx. Tel: xx.

Or you can use the normal hospital complaints procedure and contact the following person:

xx. Tel: xx.

Or you can use the formal University complaints procedure and contact :

xx. Tel: xx.

Contact for Further Information?

If you have any questions about the project please do not hesitate to contact me.

Maria Hargate

E mail address: xx.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW.

APPENDIX 7:
Children's certificate of agreement (5-8 years)

CHILDREN'S CERTIFICATE OF AGREEMENT

My name is:

I will let Maria ask me some questions about what it is like staying in hospital. I can choose if these are taped.

If I change my mind, that is OK. Or if I don't feel like answering any questions, that is OK too – it doesn't matter. I don't have to help if I don't want to. I have talked with Maria about how I will let her know that I don't want to answer any questions.

If I want my family to know what Maria and I talked about then I will tell them. If I don't, then I won't. Maria will talk to my family about this so they know that this is OK.

Maria will keep everything I tell her in a safe place so that nobody else will know that it is me that has said it. Only Maria and her teachers will know what I have said.

I can choose a pretend name with Maria so that if the things I say are used in the project, no-one will know that it is what I have said.

I will write my name in the space to show that I understand.

My signature:

Maria's signature:

Today's date:

APPENDIX 8:
Children's certificate of agreement (9-12 years)

CHILDREN'S CERTIFICATE OF AGREEMENT

My name is:

I agree to Maria asking me some questions about what it is like being in hospital. I can choose if these are taped.

I understand that I can change my mind about helping with the project. I can also choose not to answer any of the questions that Maria asks me. I have talked to Maria about how I will let her know that I don't want to answer any of the questions.

I understand that everything I tell Maria is private. Maria will explain this to my family so they know this too.

All the information that I tell Maria will be kept in a safe place. This means that no-one will know what I have said apart from Maria.

If the things I say to Maria are used in the project a pretend name will be used and not my real one. This means that no-one will know that it is me that has answered some of the questions.

I will sign my name in the space below to show that I understand and agree.

My signature:

Maria's signature: Today's date:

APPENDIX 9:
Young people's consent form

RESEARCH CONSENT FORM	
Title of Study: FAMILY CENTRED CARE: CHILDREN'S PERSPECTIVES	
Young people should complete the whole of this sheet himself / herself.	Cross out as necessary
Have you read the Young Person Information Sheet?	Yes / No
Have you had an opportunity to ask questions and discuss the study?	Yes / No
Have you received satisfactory answers to all of your questions?	Yes / No
Have you received enough information about the study?	Yes / No
Do you agree to the researcher, Maria Hargate, confidentially reviewing your nursing notes?	Yes / No
Who have you spoken to? Dr / Mr / Mrs / Ms .... Do you understand that you are free to withdraw from the study : • at any time. • without having to give a reason why. • and without affecting your future medical or nursing care.	Yes / No
Do you agree (..................................) to take part in this study?	
Signed : .... Date : .... (Young Person)	
I confirm that .... has freely agreed to participate in this study. Signed: .... Date: .... Maria E.B. Hargate	

APPENDIX 10:
Parents' consent form: Preliminary phase observation

Child Identification Number for this Study (observation only):

PARENT CONSENT FORM

TITLE: FAMILY CENTRED CARE: CHILDREN'S PERSPECTIVES

RESEARCHER: MARIA E.B. HARGATE

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my child's participation is voluntary and that both myself and my child are free to withdraw at any time without giving any reason. I also understand that my child's medical care will not be affected.
3. I agree for my child to take part in the above study.

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Name of Parent	Date	Signature

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Researcher	Date	Signature

1 copy for parent
1 copy for researcher

APPENDIX 11:
Parents' consent form: Full study

Child Identification Number for this Study (full study):

PARENT CONSENT FORM

TITLE: FAMILY CENTRED CARE: CHILDREN'S PERSPECTIVES

RESEARCHER: MARIA E.B. HARGATE

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my child's participation is voluntary and that both myself and my child are free to withdraw at any time without giving any reason. I also understand that my child's medical care will not be affected.
3. I understand that sections of my child's nursing notes may be looked at by the researcher (Maria Hargate). I give permission for this individual to have access to my child's nursing records.
4. I agree for my child to take part in the above study.

Name of Parent	Date	Signature
Researcher	Date	Signature

1 copy for parent
1 copy for researcher

APPENDIX 12:
Parents' consent form: Trust

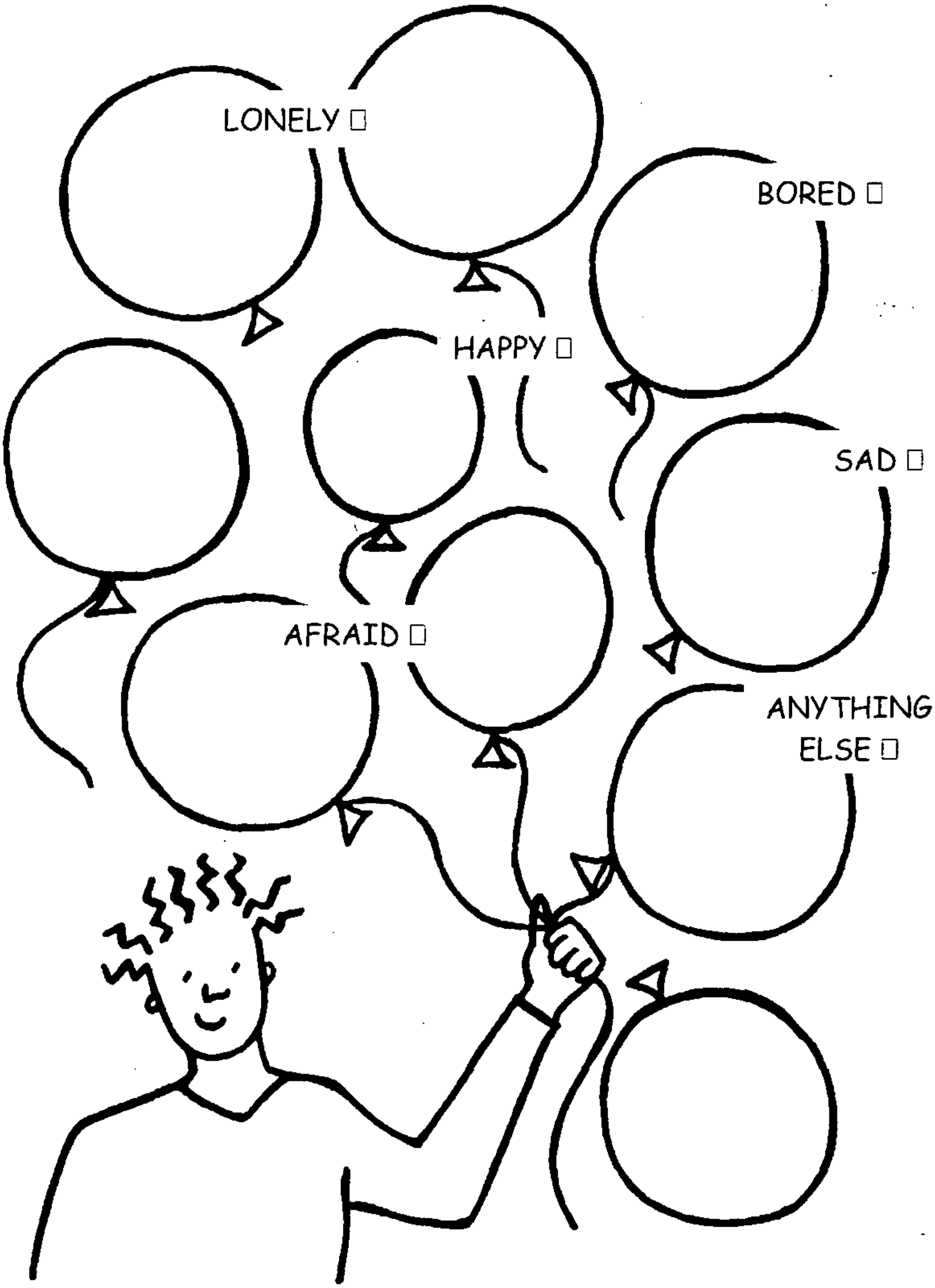
RESEARCH CONSENT FORM

Title of Study: FAMILY CENTRED CARE: CHILDREN'S PERSPECTIVES

Parents or guardians should complete the whole of this sheet himself/herself.	Cross out as necessary
Have you read the Parent Information Sheet?	Yes / No
Have you had an opportunity to ask questions and discuss the study?	Yes / No
Have you received satisfactory answers to all of your questions?	Yes / No
Have you received enough information about the study?	Yes / No
Do you agree to the researcher, Maria Hargate, confidentially reviewing your child's nursing notes?	Yes / No
Who have you spoken to? Dr / Mr / Mrs / Ms .... Do you understand that you are free to withdraw from the study : • at any time. • without having to give a reason why. • and without affecting your child's future medical or nursing care.	Yes / No
Do you agree for your child (..................................) to take part in this study?	
Signed : .... Date : .... (Parent / guardian)	
I confirm that the legal parent / guardian of this child has freely agreed to their participating in this study. Signed: .... Date: .... Maria E.B. Hargate	

APPENDIX 13:
Activity based techniques: Being in hospital makes me feel

BEING IN HOSPITAL MAKES ME FEEL…

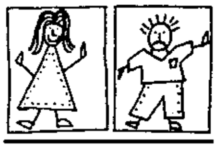


APPENDIX 14:
Activity based techniques: Choices chart

CHOICES CHART

WHO CHOOSES:	ME	DOCTORS	NURSES	MUM or DAD	SOMEONE ELSE
What time I get up					
When I have my treatment					
Who gives me my medicines					
If someone stays with me whilst the nurses are looking after me					
Whether I have liquid medicines or tablets					

APPENDIX 15:
Activity based techniques: Drawing guidelines

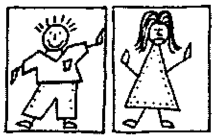


DRAWING GUIDELINES

1. Draw a picture of someone like you who is in hospital. In a think bubble write down what they are feeling and what they are thinking. Around your picture write down what worries them about being in hospital.

2. Draw a picture of a perfect hospital. In your picture either draw or write the names of the people you would like to help look after you.

APPENDIX 16:
Activity based techniques: Feelings about hospital



FEELINGS ABOUT HOSPITAL

How do you like being in hospital?

- I enjoy it
- I put up with it
- I don't enjoy it

How do you feel when you are in hospital?

- I am happy
- I am unhappy
- I am busy
- I am bored
- I am lonely

WHEN I AM IN HOSPITAL...

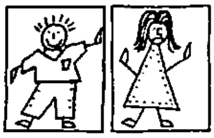
☹ I am sad when ....

☺ I feel really safe when ....

😀 I feel really happy when ....

☹ I feel frightened when ....

APPENDIX 17:
Activity based techniques: Hospital days



HOSPITAL DAYS

TIME	WHAT IS HAPPENING	WHO IS WITH YOU	WHO YOU SEE
6am			
7am			
8am			
9am			
10am			
11am			
12pm			
1pm			
2pm			
3pm			
4pm			
5pm			
6pm			
7pm			
8pm			
9pm			
10pm			

☺ My favourite time is ....

☹ My worst time is ....

APPENDIX 18:
Activity based techniques: People who are important to me

PEOPLE WHO ARE IMPORTANT TO ME

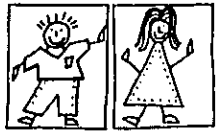
APPENDIX 19:
Activity based techniques: People who look after me

PEOPLE WHO LOOK AFTER ME WHEN I AM IN HOSPITAL

WHEN I AM IN HOSPITAL...

....	helps me to have a drink.
....	plays games with me.
....	takes my temperature
....	stays with me when the doctor sees me.
....	helps me to get washed.
....	gives me a cuddle when I am sad.
....	helps me to eat my dinner.
....	comes with me for an X ray.
....	reads me a story.
....	helps me when it hurts.
....	gives me my medicine.

APPENDIX 20:
Certificate (5-8 years)



Dear

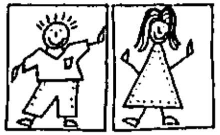
Thank you so much for taking part in my project. The things that you have told me about being in hospital have been really helpful. I hope that you will be feeling better soon.

Thanks once again!

From

Date

APPENDIX 21:
Certificate (9-12 years)



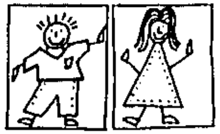
Dear

Thank you so much for taking part in my project. The things that you have told me about being in hospital have been really helpful. I hope that you will be feeling better soon.

Thanks once again!

From Date

APPENDIX 22:
Certificate (Young people)



Dear

Thank you so much for taking part in my project. The things that you have told me about being in hospital have been really helpful. I hope that you will be feeling better soon.

Thanks once again!

From

Date

APPENDIX 23:
Memo on loneliness

No.44: (Daisy aged 6 years, second admission to hospital). Described missing her friends from school and her family. Gave me a long list of people she was missing; dad, sister, brother, cousins, nan nans, grandfathers, friends, friends. Mum resident with her. Also, No 10 (James aged 12 years) stated that he's missed everything and everyone including family and pets. Links in with comments from No5 (Violet aged 9 years) who commented that even though she had her mum and both grandmas with her that she still wished for her dad. It appears that being in hospital compounds feelings of loneliness despite the presence of one or more parents or family members. Nurses appear to be depicted as strangers by children; "strangers and other people you don't know". It appears that difficulties in building up relationships with nurses' increases children's feelings of loneliness.

[Memo on loneliness]

APPENDIX 24:
Nursing establishment of ward setting

GRADE	NUMBERS OF STAFF	F.T.E.
G	1	F.T.
F	3	F.T.- 1 P.T.-2
E	14	F.T.-7 P.T.-7
D	8	F.T.-5 P.T.-3
A	6	F.T.-4 P.T.-2
Play Specialist	1	F.T.
Ward Clerk	1	F.T.

<u>Key:</u>
F.T.E. – Full time equivalent
F.T. – Full time
P.T. – Part time

[Nursing establishment of ward setting]

APPENDIX 25:
Responses to individual activities

Being in hospital makes me feel

Lonely	6 + sometimes
Bored	7
Happy	3
Afraid	5
Sad	6
Other responses: Unhappy Don't enjoy it Have to put up with it Excited Bad tempered Miss the rest of my family and friends Miss my pets Enjoy videos Theo Nurses and doctors are kind Happy: painting and drawing Sad: injections and medicine Afraid: needles Miss everyone Don't like it Don't want to be here Would rather be at home It's OK sometimes Like the food	

Choices chart

Who chooses:	Me	Doctor	Nurse	Mum Or Dad	Someone else
What time I get up	1		3		1
When I have my treatment		4	1		
Who gives me my medicines	1	5	5		
If someone stays with me whilst the nurses are looking after me			2	3	
Whether I have liquid medicines or tablets		4	1		

Feelings about hospital

	I Enjoy it	I put up with it	I don't enjoy it
How do you like being in Hospital	2	5	10

	I am happy	I am unhappy	I am busy	I am bored	I am lonely
How do you feel when you are in Hospital	1	3	1	6	7

When I am in hospital...

I am sad when...	I feel sick and have to stay in for a long time. I am sick in hospital. I have my leg dressings changed. I miss my brother and my auntie. I miss my pets. I miss everyone. I miss my hamster. I have to have a needle or an operation. My dad goes home. I see my friends and I realise that I miss them.
I feel really safe when...	Mum's here. I've got a nice nurse. My mum and nan and dad are with me. I am alone. I'm upset and someone comes after me. My mum is here. Everyone is with me. [Nurse] is looking after me. I'm not in hospital.
I feel really happy when...	I'm allowed to eat proper food. My mum is here. [Nurse] is looking after me. [Friend] has come to see me. My sister and brother and mum and dad and cousins are here. I don't have to have a blood test. The doctor says I can go home. I'm leaving.

Hospital days

Time	What is happening	Who is with you	Who you see
6am			
7am			
8am	IV's	Mum	Nurse and Mum
9am	Physio and neb	Mum	Mum
10am	Bath	Own	Own
11am	Breakfast	Mum	Mum
12pm	Dinner	Mum Nan Friends	Mum
1pm	Exercise	Me Friend Physio	Physio
2pm	Park	Friends	Friends
3pm			
4pm	IV's	Mum	Mum
5pm	Video	Mum	Mum
6pm	Tea	Mum	Mum
7pm	TV	Mum	Mum
8pm	TV	Mum	Mum
9pm	Physio	Mum	Mum
10pm	Neb	Mum	Mum
6am	Asleep	Mum	Mum
7am	Asleep	Mum	Mum
8am	Awake	Mum	Mum
9am	Physio. Medicines.	Mum	Mum
10am	School	Mum	Mum
11am	School	Mum	Mum
12pm	Dinner	Mum	Mum
1pm	School	Mum	Mum
2pm	School	Mum	Mum
3pm	Medicines	Mum	Mum
4pm	Read comic or play a game	Mum	Mum
5pm	Tea	Mum	Mum Dad
6pm	Watch telly	Mum	Mum Dad
7pm	Physio. Medicines.	Mum	Mum
8pm	Watch telly	Mum	Mum
9pm	In bed asleep	Mum	Mum
6am	Woken up by drip	No one	No one
7am	Woken up by nurse doing drip	No one	No one
8am	Watch telly	No one	No one
9am	Watch telly	No one	No one
10am	Watch telly	No one	No one
11am	Maybe computer	No one	No one
12pm	Watch telly	No one	No one
1pm	Bored	No one	No one
2pm	Bored	No one	No one
3pm	Mum comes	Mum	Mum
4pm	Mum here	Mum	Mum

5pm	Watch telly	No one	No one
6pm	Telly	No one	No one
7pm	Brother comes	Brother	Brother
8pm	Brother goes. Telly	No one	No one
8am	Nothing	No one	No one
9am	Breakfast	Mum	Mum
10am	Temperature	Nurse	Nurse
11am	Drip medicines	Nurse	Nurse
12pm	Lunch	Mum	Mum
1pm	Nothing	Mum	Mum
2pm	Nothing	Mum	Mum
3pm	Drip medicines	Nurse	Nurse
4pm	Nothing	No one	No one
5pm	Tea	Mum	Mum
6pm	Temperature	Nurse	Nurse
7pm	Drip medicines	Nurse	Nurse
8pm	Nothing	No one	No one

My favourite time is …	1pm-3pm
	Tea time
	7pm when my brother comes.
	None
My worst time is …	7pm-8pm
	Being bored
	All of it
	Morning because its boring.
	4pm because the day is going on for ever and there's nothing to look forward to.

People who are important to me …

Mum	2
Dad	2
Siblings	1
Grandmother	2
Grandfather	1
Friends	2
Pets	2
Auntie	1
Family	1
Everyone	1

People who look after me when I am in hospital

Mum (4) Dad (1)	helps me to have a drink
Mum (2) Mum and dad (2)	plays games with me
Nurse (4)	takes my temperature
Mum (3) Mum and dad (1)	stays with me when the doctor sees me

Mum (4)	helps me to get washed
Mum (3) Am too big for cuddles (1)	gives me a cuddle when I am sad
Mum (3) Myself (1)	helps me to eat my dinner
Mum (1)	comes with me for an X ray
Mum (2) Me (1)	reads me a story
Mum (3) Nurse (2)	helps me when it hurts
Nurse (3) Mum and nurse (1)	gives me my medicine