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**Reframing a sense of self: a constructivist grounded
theory study of children's admission to hospital for
surgery**

Karen Ford

RN, BN, MN, Cert Paed Nsg

Submitted in fulfilment of the requirements for the Degree of

Doctor of Philosophy

University of Tasmania

November 2010

Statement of Original Authorship

I hereby declare that this thesis is my own work and contains no material which has been accepted for a degree or diploma by the University of Tasmania or any other institution, except by way of background information and duly acknowledged in the thesis, and to the best of my knowledge and belief no material previously published or written by another person except where due acknowledgement is made in the text of the thesis, nor does the thesis contain any material that infringes copyright.

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Statement of Ethical Conduct

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University.

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Abstract

Children are significant users of healthcare and their needs are different to those of adults. Whilst important gains have been made in children's hospital care since the last half of the 20th century, there is a recent trend to reduce dedicated paediatric services in Australia. In order to provide healthcare services that are child centred and that truly respond to the needs of children, children's perspectives on their healthcare are essential. Yet the inclusion of children's perspectives in health services and research is lacking. It is through listening to, and hearing children, that health care can move closer to meeting their needs. This qualitative study explored the experiences of 10 primary school aged children (six to twelve years of age) admitted to hospital for surgery, from their perspective. A constructivist grounded theory approach was used that incorporated flexible, child centred research techniques including interviews and the 'draw and write technique'.

This thesis presents a substantive theory: children's reframing of their sense of selves to incorporate the experiences of hospitalisation and surgery. The children were active participants embedded within the phenomenon. Admission to hospital for surgery presented a form of adversity for the children in what was an embodied experience of contrasts. Major concepts of the experience were: 'being scared'; 'hurting'; and 'having fun'. There were two major processes the children engaged in for reframing their sense of self to incorporate the experience. The first was around their meaning making activities, expressed as 'coming to know' and the second was their ability to move on from the adversity and reintegrate the experience into their normal lives, expressed as 'bouncing back'. In order for the children to successfully incorporate the experience into their sense of self, a supportive context or holding environment was necessary, expressed as 'being held'.

Children were the primary source of knowledge about their views and experiences for this study. The findings highlight the importance of centring children's healthcare on the needs of children and their families. The findings suggest that ongoing problems with paediatric practices continue to impact negatively on children's experiences of hospitalisation. Although there is a body of evidence about what constitutes best practice, in reality, practices fall short of these recommendations.

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Finally, special thanks to my family, Ross, Paddy, Annie and Will: Thankyou for keeping me grounded in family and my apologies for time away from you, for poor housekeeping and thrown together meals! I'm free next weekend – what would you like to do?

Childhood has its own way of seeing, thinking and feeling, and nothing is more foolish than to try and substitute ours for them (Rousseau in *Emile*, 1792).

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Chapter 1: Children's experiences of hospital – why aren't their needs met?

From the first ward we seek to enter we are admonished by our senses to turn back. We have barely looked in when the faint, sweet odour of chloroform hanging in the air, the hiss of the antiseptic spray machine, and the screens placed round a cot informs us that one of the surgeons is conducting an operation. The ward is all hushed in silence, for the children are quick to learn that when the big, kind-eyed doctor is putting a little comrade to sleep in order to do some clever thing to him to make him well, all must be quiet as mice. There is no more touching evidence of the trust and faith of childhood than the readiness with which these children surrender themselves without a pang or fear into the careful hands of the doctor' (From the *Strand Magazine*, 1891 cited in Lansdown 1996, p13).

The views of the children who experienced surgery in the late 19th century presented in the quote from the *Strand Magazine* can only be speculated on. The children's descriptions of their experiences are likely to be very different to the adult perspective that forms the historical record. The 'quiet as mice' children who 'surrender themselves without a pang or fear' in this silent ward were most likely extremely frightened of what might happen to them in a place where surgical procedures were performed behind the screens placed around their cots. The extract provides an example of the silence and powerlessness of children in historical works, but the absence of the voices of children remains a notable feature of the present healthcare environment.

Children are significant users of the healthcare system and up to one in ten admissions to hospital are children and young people. The majority of these admissions are unexpected, as is much surgery on children (Department of Health 2003). In 2006, almost 4 million Australians (or 20% of the total population) were children aged under 15 years and in 2005-06 there were 536,978 hospitalisations among children in this age group (Australian Institute of Health and Welfare 2008, p274). With this number of children hospitalised each year, children's experiences of hospital are clearly important.

Unfortunately, children continue to experience physical harm, unnecessary pain, fear and anxiety during and after healthcare experiences (Nicholson and Clarke 2007, p14). These negative experiences matter because hospitalisation in childhood can

have significant impacts on them in physical, emotional and psychosocial terms. Overall, the healthcare needs of children are very different to the needs of adults and children have unique vulnerabilities and patient safety risks (Royal Australian College of Physicians (RACP) 2008, p3). Therefore it is necessary that healthcare services are designed around, and responsive to, children's needs. Services for children should be crafted around the journey the child makes through their admission to hospital. One way of achieving this is to see those services through their eyes (Department of Health 2003).

Yet children's own perspectives of healthcare are lacking. In order to find out what children have to say and so develop more complex understandings of their experiences, studies need to be undertaken that include children in the research process. Research grounded in children's perspectives will allow the development of theories of children's experiences of illness and healthcare, which will inform service design and delivery. In response to this need, there is a growing body of research that places much greater emphasis on children as active participants in research. The thesis adds to this body of work and presents a theory of children's experience of hospital. As such, the thesis adds to understandings of children's hospitalisation. The theory was developed by exploring the perspectives of children as they experience admission to hospital for surgery.

Social and political drivers to improve children's experiences of hospitalisation

Initiatives to address the negative impacts hospitalisation has for children have been a feature of paediatrics and child healthcare for some time. James and Joyce Robertson worked to alleviate the harmful effects of hospitalisation on children in the 1950s (Shields and Nixon 1998, p18). Their work was influenced by the hospitalisation of their own daughter. The classic film *A two year old goes to hospital* (Robertson 1952) depicts the story of a two and a half year old child, Laura, who spent 8 days in hospital for a surgical procedure. The work highlighted the potentially damaging effects of hospitalisation on children. The film received a hostile response when initially shown to medical and nursing personnel - these personnel were of the belief that the best interests of children were that parents

should not be present during a child's admission. James Robertson reported on the responses of hospital staff to his observations:

As fieldworker I discovered that there were often limits to the agreement to be had in discussion with nurses and paediatricians not only about the meaning of behaviour in certain young patients but also about the actual facts of that behaviour... I was thought at times to be diminished in my objectivity by becoming over-identified with the children; I in turn considered that a contrary phenomenon tended to occur in hospital staffs, namely that defences had built up in them against the painful recognition of the extent to which young patients are unhappy - not only in the initial phase of overt fretting but in later, stages of being 'settled in' (Bowlby and Robinson 1953, p425).

Despite initial opposition to the work of Robertson and others who took a similar position, there was an increasing movement for change in the care of children in hospital.

Social and political responses to the needs of hospitalised children have resulted in recommendations regarding their care in hospital. These recommendations have acted as key drivers for important changes to health care practices that are responsive to children's needs and rights. The *Platt Report* (Ministry of Health 1959) is a political work that served as a landmark in child health care. Also known as *The Welfare of Children in Hospital*, the *Platt Report* was released in the United Kingdom in 1959. Recommendations contained within the report led to significant changes in the care of children in hospital. These changes included attitudes towards children, so that their needs were to be given a central place in the planning and provision of their care.

Greater attention needs to be paid to the emotional and mental needs of the child in hospital, against the background of changes in attitudes towards children, in the hospital's place in the community, and in medical and surgical practice. The authority and responsibility of parents, the individuality of the child and the importance of mitigating the effects of the break with home should all be more fully recognised (Ministry of Health 1959).

An international response to children's health care needs is the World Health Organisation's Child Friendly Healthcare Initiative. This program aims to achieve internationally applicable standards for practices in hospitals and health centres. The initiative aims to achieve respect for children's rights; children's survival and

avoidance of morbidity; their protection from unnecessary suffering; and their informed participation in treatment (Southall et al. 2000).

Social initiatives that focus on improved circumstances for hospitalised children also include the formation of consumer advocacy groups. In Australia, the Association for the Welfare of Children in Hospital, now the Association for the Wellbeing of Children in Healthcare (AWCH), lobbies for care of children in healthcare. A *Recommended Health Care Policy Relating to Children and their Families* was released in 1974 and further revised in 1999 (AWCH, 1999). The policy was an important development for the care of hospitalised children in this country, which led to considerable changes to the way hospitalised children were cared for.

More recently, the *National Standards for Children and Adolescents in Health Care* (RACP 2008) have been released¹. The standards are intended for use in all health services where children and adolescents are cared for in Australia. They aim to ensure quality care for children in an environment that is 'safe and appropriate for the age and stage of development of the child or adolescent' (RACP 2008, p3). The standards recognise the special healthcare needs of children; that children need to be cared for by specially trained staff; and that children require separate facilities in all areas of the health care service where they are cared for. The standards advocate for children in healthcare, however, it is not clear that children, who are *key* stakeholders, were involved in their development (RACP, 2008, p3).

All of these initiatives reflect the broader concern for children's rights espoused in the United Nations Convention on the Rights of the Child (UNCRC) (United Nations (UN) 1989). Policies and practices in health services should reflect the rights of children and their families and be informed by the UNCRC (RACP 2008, p5).

¹ The *National Standards for Children and Adolescents in Health Care* were developed in collaboration between professional and consumer organisations. The organisations include the Royal Australian College of Physicians; AWCH; Children's Hospitals Australasia; and the Australian College of Children's and Young People's Nurses.

Children's healthcare rights

The UNCRC acknowledges the status, role and rights of children and their special needs and situations. The Convention, adopted by the United Nations General Assembly in 1989, 'protects children's rights by setting standards in health care, education and legal, civil and social services' (UN 1989). In ratifying the Convention, signatory countries pledged to review their laws and practices to comply with it. A number of the rights relate directly to the provision of children's healthcare, as outlined in Table 1 (p6).

Initiatives such as those mentioned above mean that children's contemporary experiences of hospitalisation are in many ways significantly different to those of earlier times. These changes manifest the rights of children as outlined in the UNCRC (UN 1989). For instance, the child's right to remain with their parents is expressed in Article 9 of the Convention. One important feature in contemporary children's healthcare is increased parental presence and support. Hospital rules that limited parental visits have been replaced with policies that support parent's residing in hospital. Parents are now able to be with their children during the child's hospitalisation (with some important exceptions for this study, such as around the time of surgery and recovery).

Current and future trends for care of children in hospital

As well as seeking to meet children's rights, a number of other changes impact on children's healthcare and hospitalisation. Changes include the types of surgeries conducted on children, for example, the development of laparoscopic surgery techniques and the decreased incidence of tonsillectomies. The move to same day surgery means that the incidence of overnight admissions to hospital for surgery is much decreased (Darbyshire 2003, p292). Reductions in overall length of hospital stay and the child friendly practices that have been incorporated into paediatric care are other changes (Peterson et al. 1997, p336, Darbyshire 2003, p292). Many of these changes have been in response to children's rights in healthcare and the findings and recommendations of earlier studies and reports. Others have been through economic imperatives and technological and clinical advances. Some of the changes have decreased the lasting negative effects of hospitalisation and improved children's reactions (Peterson et al. 1997, p336-337). Others have had implications for children

and families including their roles in the recovery process. An increased burden and responsibility on parents in providing care for their child is one such impact (Darbyshire 2003, p303).

Table 1: Articles of the UN Convention on the Rights of the Child that relate directly to children's healthcare (Nicholson and Clarke, 2007)

Article	As the article relates to healthcare
2	Equal rights to care with no discrimination for any reason
3	Whenever an adult makes any decision about a child or takes any action that affects the child this should be what is best for the child
6	The right to live
7	The right to name and nationality, and to be cared for by parents
9	The right to remain with parents, or in contact with parents, unless this is contrary to the child's 'best interests'
12 and 13	The right to receive information and express views and ideas freely
19	The right to be protected from any form of harm, including violence, neglect, and all types of abuse
23	The right of those with a disability (physical or mental) to lead a full and decent life within their community
24	The right to the highest standard of health and medical care attainable
27	The right to a standard of living adequate for physical, mental, spiritual, moral and social development
28	The right to education
30	The right of a child belonging to an ethnic, religious or linguistic minority to enjoy their culture, practice their religion and use their language
31	The right to rest and play
38	The right to be protected from and during armed conflicts, and not to be recruited to take part in hostilities, especially before the age of 15 years
42	Is about the duty of the state to ensure that children's rights relating to health are made known

Significant gains have been made in children's hospital care since the last half of the 20th century. However, a recent trend to reduce paediatric services in Australia is apparent. A survey conducted by AWCH in 2008 found that in the previous 15 years in Australian public hospitals treating children, there had been a 30% decrease in the number of dedicated paediatric units. In addition, 35% of hospitals did not routinely accommodate children in separate areas to adults (Bennett 2009, p3). The decrease in paediatric specific care areas and growing trend toward co-locating children with adults is the result of pressures on beds and budget restrictions. This is despite evidence and standards that indicate the interests of child and adult patients are not served by such moves (RACP 2008).

The special needs of hospitalised children were outlined in the *Garling Report* (Garling 2008). The report presented findings from an inquiry into acute care services in the Australian state of New South Wales. As well as the increasing trend for children to be cared for alongside adults, Garling (2008) reported on the increased resources required for caring for children:

The treatment of children is often more time-consuming and requires higher staffing levels than treatment for adults. For example, the nurse to patient ratio for adults in a post anaesthesia recovery area is 1:2 or 1:3 and for children it is 1:1 until they meet discharge criteria. It takes 2 staff members to put a drip into a child, one to carry out the procedure and the other to hold the child still. As such, the cost of treating a child is greater than for an adult (p107).

Increasing pressures on resources place further strains on attempts to provide quality care for children who are hospitalised. The increasing healthcare needs of an aging population is one example of this (AWCH 2008, Bennett 2009, p3). This is despite recognition of the needs for children who are hospitalised. These needs are identified in reports such as the *Platt Report* and *Garling Report*, and recommendations articulated in standards and guidelines for the hospitalisation of children. It is in this political and social context, that the current study is positioned.

The importance of children's perspectives of their healthcare

In the years since the signing of the UNCRC (UN 1989) there have been significant changes to laws and practices affecting children. However, the rights of children are not universally met. Even in developed countries with advanced healthcare systems,

there is still work to do to ensure children's rights are met (Nicholson and Clarke 2007, p14). For children to be recognised as important, it is essential for them to be heard in matters of concern to them (UN 1989). Incorrect assumptions about the needs and concerns of children can be limited with children's input and their input can strengthen healthcare practices, service development and education of healthcare professionals (Carter 2006-7, p182). Just as political imperatives have driven the need to improve conditions for children in hospital, there has also been a move to involve children in research (Greig et al. 2007, p157). Children's participation in their healthcare as well as their participation in research is essential (Darbyshire et al. 2005, p420). Children's voices may be encouraged when the child is positioned as an active agent in the research process and when child centred research techniques are used (Woodhead and Faulkner 2000, p31).

Children's absence in research

However, children have traditionally been denied the rights of participation in research, lacking visibility and their voices have gone unheard (Darbyshire et al. 2005, p419). Children's lives have at best been explored through the views and understandings of their adult caretakers providing proxy information (Christensen and James 2000, p2, Scott 2008, p87). At worst they have been invisible. The traditional approach to researching children's experiences has been based in research *on* or *about*, rather than research *with* children. This positioning of children in research has been easily maintained because most research projects involving children are initiated by adults with the aims also determined by adults (Hill 2005, p67). Traditionally, children have been viewed as being incompetent, unreliable and developmentally incomplete. When children are viewed as being inadequate and unreliable reporters of their views and situations, researchers rely upon reports from adults 'close to children'; the observation of children's behaviours; and experimentation on children (Alderson 1999, p35).

Children's lack of agency in research means that research involving them has focused on children as objects rather than as active participants. Children are thus viewed as 'child variables rather than children as persons' (Greene and Hill 2005, p1). Up until the mid 1990s, the positivist paradigm dominated research involving children. The emphasis therefore was on measurement, abstraction and statistical

relationships (Hill 2005, p62). This focus means that much is known about some aspects of children's lives, including for example, children's physical growth and what constitutes a healthy diet for children, but less about children's understandings and experiences (Alderson 1999, p35).

Reasons for the absence of children's voices in research are many. They include inertia of practice; that adults have traditionally been accredited with knowledge on subjects concerning children; a perception that experience and power lie with adults; that interviewing children has been seen as too problematic to yield benefits; perceived practical and ethical issues; and that children are believed to lack the communication, cognitive and social skills that are the prerequisites of good respondents (Scott 2000, p101). In addition, children's interests can be at odds with adults in positions of power, for example, parents, teachers and medical personnel (Hendrick 2008, p43). This means that adults may have limited motivation to increase children's participation. Without an authorial voice, children have little or no opportunity to contest adult accounts and children's voices remain 'muffled' (Hendrick 2008, p47).

Children's rights to participation in research

Children's rights to involvement in research, and that children's perspectives of their experiences should be better valued and understood, is afforded to children in the UNCRC (UN 1989). Children's right to hold and express their personal beliefs is contained predominantly in Articles 12 and 13 of the Convention. Article 12 has particular relevance to research that explores children's perspectives and experiences:

State parties shall assure to the child who is capable of forming his or her own views freely in all matters affecting the child, the views of the child be given due weight, in accordance with the age and maturity of the child.

Article 13 states:

The child shall have the right to freedom of expression; this right shall include the freedom to seek, receive and impart information on ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art or in any other media of the child's choice.

The Convention supports the concept of the child's active participation in the research process. The Convention also requires that the best interests of the child are assessed and respected and that they be given the opportunity to be heard. This means that children need to be listened to and for them to be active participants in the research process.

Children as active participants in research

The best people to provide information on the child's perspective, actions and attitudes are children themselves (Scott 2000, p121, Mayall 2000, p99). In recent years, particularly within social science research, there has been a fundamental shift in understandings about children and a repositioning of them in research. Children are becoming more the subjects, or participants, rather than the objects of research. There is an increased understanding of children as 'social actors, communicators and meaning makers from the beginning of life, trying to make sense of their social world, in the various cultural contexts they inhabit' (Woodhead and Faulkner 2000, p27). Such shifts have been less evident in health research.

Children are increasingly recognised as being epistemologically privileged when it comes to research relating to matters of importance to children (Balen et al. 2006, p31). Adults, such as parents, teachers and health professionals, can provide important insights into children's behaviour. However, including children in research relevant to them provides a much more comprehensive account of the child's life (Scott 2000, p107). It is increasingly recognised that adult perceptions of children's thinking, actions or needs can differ from what children themselves say. This is demonstrated in a number of studies, including for example, work by Callery, Milnes, Verdyn and Couriel (2003) on parents and young people's understandings of childhood asthma. Further, adults on their own are not able to fully understand the world from the child's point of view. Children are needed to explain their world view, as argued by Christensen and James (2000):

Only through listening and hearing what children say and paying attention to the ways in which they communicate with us will progress be made towards conducting research with, rather than on, children (p7).

Children's participation in qualitative research that invites children to dialogue, affords children recognition and respect. Such research allows the views and

experiences of children to be considered in policy and practice, where planning and decisions concerning them are largely determined (Graham and Fitzgerald 2010, p5).

Child centred research approaches

When children are involved in research, researchers need to consider using appropriate research methods. How the researcher 'sees' children informs the choice of research methods adopted. Four views of children have been described in literature relating to research with children and these are: 'the developing child'; 'the tribal child'; 'the adult child' and 'the social child' (O'Kane 2008, p130).

When a staged, developmental frame is applied to children, as in the view of the developing child, children are seen as being in a state of becoming or 'not yet being'. Children are then positioned as being 'less' than adults (Hendrick 2008, p42). The tribal child is viewed as competent and part of an independent culture which can be studied in its own right, but not as part of the same communicative world of the researcher. In both these constructions, children are not provided with the same status as adults (O'Kane 2008, p130). In contrast, the adult child and social child do have this capacity. The adult child is viewed as socially competent like an adult, and under this view, research processes for adults can be seen as being easily adapted for use with children.

The social child is viewed as having different, although not inferior, abilities and competencies. At the same time as stressing the uniqueness of children, the social child view seeks to capture and express the diverse dimensions of childhood, taking into account the differences (O'Kane 2008, p130-131). The use of child-centred research methods can allow increased engagement with child participants. These include the use of different and flexible methods of communication that incorporate non-invasive and non-confrontational methods. Such methods can help to address ethical problems and power imbalances, and allow the child to inform, make decisions on, and also shape the research (Garden 2007, p23).

In keeping with the social child view, children in this research were approached as social actors. Research techniques that enabled effective engagement with children were drawn upon to facilitate children's participation in the research on their own terms and in ways that would result in increased understanding of their experiences.

Child centred approaches include ethical and practical implications with respect to ability and inherent power relations between the researcher and researched – the adult and the child (Mayall 2008, p111). These approaches recognise that traditional methods used to engage participants may not be the best to engage children and give them a voice in the research process. They also recognise that issues of consent and confidentiality, competence and knowledge in research with children require special considerations (France et al. 2000, p152). This work recognises that children's participation in research is essential for theoretical, moral, ethical and practical reasons. Children are carriers of their own experience and research with children as participants is crucial if their needs are to be met. Research that involves children as participants requires the use of techniques that ensures their interests are served. For example, children's participation in research has drawn closer attention to the ethical and methodological issues related to research with children (Graham and Fitzgerald 2010, p2).

Research approaches and ethical positions have largely been designed for adults, with untested relevance for research with children (O'Kane 2008, p126). Ethical issues in research with children relate in part to children's understandings and experience of the world that is different to that of adults, and also to the ways children communicate. Power relations (addressed below) also provide a significant test. The challenge for researchers working in historical and social contexts where children's voices have been marginalised is to find ways to break the power imbalance and to create spaces that enable children to speak out and to be heard (O'Kane 2008, p126).

Disparities in power relations between adults and children present a major challenge for conducting research with children that cannot be ignored in the research process. Indeed, structurally, children are made vulnerable because of a lack of political, economic power and civil rights as a result of historical attitudes and assumptions (Garden 2007, p23). Because adults have authority over them, children often find it hard to express dissent, to disagree or say things that they think an adult might find unacceptable. In addition, children are generally physically weaker than adults and usually have less well developed coping strategies. Many children are not used to being consulted or may feel their views are disregarded (Hill 2005, p63). This

perceived incompetence and weakness results in children being viewed as especially vulnerable to persuasion, influence and even harm – both in life and in research (Hill 2005, p63).

In summary, there is a growing acknowledgement of children as persons in their own right who contribute to and shape their everyday lives and who are worthy of recognition, respect and voice. Further, children's experiences, status, rights and wellbeing are central to healthcare services for children. There is a clear need for studies into children's experiences of hospital that use methods appropriate for research with children as participants. This in turn presents a clear rationale for this study and links directly with the research aim.

A study that explores children's admission to hospital for surgery

The aim of this research was: *to explore children's admission to hospital for surgery from their perspective in order to develop a substantive theory.*

This study explored children's admission to hospital for surgery from the perspective of children themselves using a constructivist grounded theory approach as the research method (Charmaz, 2000, 2005, 2006). The primary intentions of the study were to:

- Consider children's preoperative, intraoperative and postoperative experiences, as described by children;
- Explore the thoughts, feelings and perceptions of children who undergo surgery; and
- Theorise about the phenomenon in order to increase understandings of children's experiences of admission to hospital for surgery.

The first and most important issue that this thesis addresses is the experiences of children who are admitted to hospital for surgery from their perspective, addressing the contexts, meanings and processes of this studied phenomenon. The other distinctive areas addressed in the thesis relate to conducting research with children as participants and the use of a constructivist grounded theory approach in research with children. The work provides insights into methodological and practical issues around

children's involvement in research and children's participation when a constructivist approach is used - where child and researcher engage together in developing understandings. The work is informed by these areas, and contributes to the current knowledge in these areas.

The research acknowledges children's position as active social agents and central informants of their own lives. Children's perspectives were given prime positioning in the research. The intention was to dis/uncover what this experience means for the children concerned, the processes they were engaged in, and the contexts in which the experience was situated. The work is important because previous studies have largely explored children's understandings and experiences of surgery through the views and understandings of their adult caretakers, providing proxy information. Children themselves have had limited opportunities for participation and to voice their thoughts, feelings and perceptions. Researching children's experiences and understandings of surgery is critical if care is to be responsive and relevant to their concerns and needs. By exploring the ways children experience, conceptualise and understand their surgery, practice can be progressed in ways that are truly child centred and in the best interests of the child.

Exploring 10 primary school age children's experience of surgery was achieved through their narrating about that experience. Interviews explored children's cognition, emotion and behaviour as well as their needs, wants, expectations, experiences and understandings of surgery. Children's drawings and stories furthered understandings as did my own observations of children's interactions in the time around their admission for surgery, including the pre, intra and post-operative periods. The literature was also drawn upon as an additional data source, whilst recognising that children are largely silent in the literature to date.

The theoretical location: Constructivist grounded theory

In order to engage children as social actors, a constructivist grounded theory approach, underpinned by symbolic interactionism was chosen. Grounded theory is recognised as a suitable method for research with children (Woodgate 2000, p194) and provides a method to effectively engage with children as participants. Grounded theory approaches do not make predetermined assumptions about participants lives, and as a result, children's feelings and experiences can be empowered as opposed to

overpowered in the research process (Garden 2007, p30). A constructivist grounded theory approach in this research acknowledged children as co-constructors and included their views and concerns. This approach recognised them as experts and active participants in the research process. Children were consulted and involved in a meaningful way about their healthcare and understandings were thus increased.

Grounded theory is a systematic but flexible method for collecting and analysing qualitative data to construct conceptual frameworks or theories directly grounded in the data. A constructivist approach assumes a relativist ontological position where the world consists of multiple individual realities. Constructivism begins with the experience and explores how members construct it. Constructivists enter the phenomenon, to the extent they are able, and gain multiple views of it and locate it in its complexities. The interpretation of the studied phenomenon is in itself recognised as a construction (Charmaz 2006, p187). Constructivist grounded theory results in the construction of interpretive renderings of the world of study. The approach fosters openness and empathetic understanding of participants' meanings, actions and worlds and has the potential to transform practice (Charmaz 2006, p184).

For all these reasons, constructivist grounded theory provided a suitable ontology for this research project that sought to understand children's meanings, where the emphasis was on children as unique beings, and the focus was on the world as experienced by the participant children.

Reflexivity and situating myself

Reflexivity is the process of reflecting critically on the self as researcher...it is a conscious experiencing of the self as both inquirer and respondent, as teacher and learner, as the one coming to know the self within the processes of research itself (Guba and Lincoln 2005, p210).

Reflexivity is essential in any qualitative research. In research with children, reflexivity regarding the positioning of the researcher and the participant is even more significant as children are a vulnerable group. Children who are undergoing surgery could be seen as being doubly vulnerable, requiring extra vigilance. Therefore, this research required increased reflexivity and awareness of the relationship between myself, as researcher, and the children, who were the participants (Barker and Weller 2003, p210). Critical reflexivity was required

relating to my presence and accountability in the research as well as the use of prior experiences and knowledge (Clarke 2005, p13).

Consistent with a constructivist grounded theory approach, transparency about the subjective approach and interpretations made from the research process were important. Reflexivity was needed about what I brought to the scene, what I saw, and how I saw it (Charmaz 2006, p15). Reflexivity began with understanding the importance of my own values and attitudes within the research process - understandings required from the outset. It entailed taking a critical look inward and a reflection on my own lived reality and experiences. Questions that were part of this process included 'how does who I am impact on the research process?' and 'what shapes the questions I choose to study and my approach to studying them?' (Nagy Hesse-Biber 2007, p326). Creativity is an essential ingredient of the grounded theory approach, and my experiences are acknowledged as a source of sensitivity that enabled creativity: 'The theories we carry with us in our heads inform our research in multiple ways' (Strauss and Corbin 1998, p47). Assumptions and stances needed to be made explicit, rather than remain tacit.

Qualitative researchers speak of themselves as human beings, being 'the research instrument' and of being 'immersed' in the data in order to understand it. Researchers try to be in tune with their own thoughts, feelings and sensations which may alert them to new insights (Alderson 2001, p14).

My role and responsibility as researcher was 'as an actor, designer, interpreter, writer, constructor of the data, ultimate arbiter of the accounts proffered, and as accountable for those accounts' (Clarke 2005, p12). The central role in deciding on the data gathered and the meanings or interpretations made required an openness, transparency, reflexivity and critical stance about perspectives and experiences and how they may have influenced the study. These influences needed to be highlighted rather than ignored, in order to ensure the usefulness and quality of the research.

As researcher, my personal, political and professional interests are acknowledged as I brought to the research my own experiences and world view. These include my views of children, children's status and children's healthcare, of research and research with children. The research recognises the interview as an active relationship between the interviewer and the child participant and the research is

child-centred in its focus. The choice of research method reflects a strong personal affinity with qualitative research approaches; an understanding that there is no one truth; and that individuals, including children, are active agents in constructing their realities. The aim for the research to be child-centred in its approach reflects a personal and professional position in supporting the interests of children and young people.

In reflecting on my perspective, some of the underlying assumptions that I brought to this work are acknowledged. The work is informed by my experiences as a paediatric nurse, an educator and also as a parent of children who have themselves undergone surgery. I have worked as a paediatric nurse for many years, providing care for children who have undergone highly specialised surgical procedures as well as those considered more routine. (However, I acknowledge that for most children and their families, there is no routine or minor surgery.) In recent years I have been a nurse educator, teaching postgraduate nurses in the specialty of paediatric nursing. I am also the parent of (now) young adult children, and two of my children have been admitted to hospital and undergone surgical procedures whilst they were of primary school age.

My experience as a paediatric nurse means that I have a high degree of familiarity with hospital environments in general, and particularly in paediatric care settings. This level of familiarity presents the risk of taking for granted aspects of the process children are engaged in, forgetting for example how foreign the hospital environment is for children. Experience as a nurse educator in paediatrics means that I have an understanding of theories of child development and the effects of hospitalisation on the child and family and an understanding of contemporary paediatric practice. My experiences ‘on the other side of the bed’ as a parent of children undergoing surgery provided me with a different perspective. I remember very clearly, for example, the overwhelming emotion I felt each time I left my child in the operating theatres following their induction of anaesthetic. The first time I experienced this emotion I was quite unprepared for its force. Yet as an experienced paediatric nurse, I thought I had a good understanding of the effects such experiences had on families. The experience of being a parent of a child undergoing surgery provided new insights and understandings. When I asked my son about his memories of hospitalisation for

surgery he said it was ‘painful, scary, mostly boring and sometimes fun.’ My daughter agreed with his summation of the experience. During the course of this research, I found these words, or words very similar to these echoed by the children participating in the research.

I acknowledge that no two individuals will have the same experiences and this is the case for children, their parents and for those who care for them within the hospital setting. I have no experience myself of having been hospitalised as a child. However, it was apparent from speaking to people during the course of this study, that memories of childhood hospitalisation and surgery remain very clear for many into adulthood. Remaining transparent and conscious of these perspectives and not assuming that the children participating in the study would share these perspectives and experiences was important. They then served as tools that assisted in understanding and exploring children’s admission to hospital for surgery, from the perspective of children themselves.

I am aware that the notion of giving ‘unmediated “voice” to the unheard - from “their own” perspective(s)’ (Clarke 2005, p14), is problematic as all reports are deeply mediated by the researcher. Important questions for reflection during the study included to what extent were different perspectives given voice, and who or what might be omitted or silenced, with intent or unwittingly. I needed to be aware of a temptation to present the data in a way that suited my own intent, and to be careful in the way I addressed contradictory responses (Clarke 2005, p15). There were points of crisis in this work where these questions assisted me in the research process. How was I to deal with data that did not conform (for example the drawings not by the child, but by the parent)? How was I to deal with the ‘negatives’ and the instances where I was at risk of possible ‘over interpretation’ of the data?

During the course of this work I have reflected again and again on the notion of ‘giving voice’ and of presenting children’s perspectives. In order to be true to the children’s meanings and their trust in me, I have endeavoured to present the children’s different perspectives from as close to the experience as I was able to get. In addition, I have respected the children’s contribution to the work in whichever way they chose.

Thesis structure

The thesis has been organised into 9 chapters. This Chapter provides an introduction to the research topic; presents the purpose of the research and its rationale; and includes a discussion on reflexivity and my own positioning in the research, consistent with a constructivist grounded theory approach.

Chapters Two and Three provide a preliminary review of the literature in order to set the stage for the research and provide a context for the research project. Chapter Two provides an overview of children's place in society and of children's healthcare and hospitalisation from a social, cultural and historical perspective. The chapter highlights the lack of children's voices in the historical, social and healthcare contexts.

Chapter Three presents a discussion on research involving children, including research where children have been the objects of research as well as the recent repositioning of children as participants in research. The chapter considers the theoretical and ethical issues when conducting research with children as participants. It includes the tensions that arise in this complex and sensitive area and focuses on child-centred research techniques that can be used to access children's experiences consistent with the intent of the study.

Chapter Four addresses methodological considerations. The chapter includes the evolution of grounded theory and focuses on the chosen approach for this study, constructivist grounded theory as described by Charmaz (2000, 2005, 2006). Symbolic interactionism, recognised as the theoretical perspective underpinning grounded theory, is discussed in relation to research with children.

Chapter Five outlines the methods as applied to the research, including application of constructivist grounded theory and the use of flexible research techniques in research with children, including the draw and write technique.

Chapter Six and Seven present the findings of the analysis of children's admission for surgery. The findings are presented under the areas of the phenomenon as experienced by the children; the processes they were engaged in; and the context within which they experienced the phenomenon. The ways that children made

meaning of their experience; their resilience and coping; and the important context of a facilitating environment are discussed.

Chapter Eight focuses on the interpretation and theoretical renderings of the findings and presents the substantive theory of primary school age children's admission to hospital for surgery, from their perspective.

The final chapter highlights how the research question was answered and the broader implications of the study findings for paediatric nursing and research.

Conclusion

Children are significant users of healthcare, their needs are different to those of adults, and their hospitalisation has physical, emotional and psychosocial impacts on them. In addition, political, social and economic contexts influence children's healthcare. In order for healthcare to more appropriately meet children's special needs, understandings of children's perspectives of this aspect of their lives is essential. This area of study deserves attention, in light of international and national guidelines, policies and standards for children in healthcare, but also because of ethical and moral imperatives and children's fundamental rights. However, children's voices are not often heard, in healthcare, and in research in general, and so there is a gap in understandings of what the experience of healthcare means for children themselves. This study goes some way to addressing this gap by exploring one aspect of children's healthcare – that is admission to hospital for surgery of children aged 6 to 12 years, from their perspective.

The research design places children at the centre of the research and the methods chosen facilitate the exploration of children's meanings using approaches that are suitable for children of primary school age. In this study, children were viewed as social actors and the use of child centred research techniques allowed for the increased engagement of children. The current study contributes to our understanding of children's healthcare needs when they are hospitalised for surgery. The work is consistent with the intentions of the UNCRC (UN 1989) as well as the recommendations for the increased involvement of children in healthcare.

The next chapter considers changing social, political and historical circumstances and their influence on children's status in society and healthcare and contextualises the research.

Chapter 2: Locating children - in society and in healthcare

This the child six summers old
Is not worth much when all is told.
But one must take every care,
To see that he is fed good fare,
For he who does not start life well
Will finish badly, one can tell... (13th Century Poem, cited in Aries 1962, p20).

The purpose of this chapter is to explore the social, historical and political contexts of children: specifically the place of children in society; children's healthcare and hospitalisation. By situating children in terms of these areas, this research project is grounded and contextualised. The discussion also serves to locate and facilitate understanding of children's experience of hospitalisation for surgery. Examining the past position of children in society and in healthcare provides a frame for better understanding the issues impacting on children's experience of admission to hospital for surgery in the present. Before continuing, however, it is timely to consider the role the literature review has in a grounded theory study.

The role of the literature review in this grounded theory study

In keeping with the grounded theory method, this preliminary literature review involves consideration of a range of issues surrounding the phenomenon of interest of the study, that is, children's experiences of admission to hospital for surgery, whilst avoiding the literature most closely related to that study. The preliminary literature review relates to aspects of the broad research topic that is children's admission to hospital and surgery, from their perspective, and serves to set the stage for the subsequent chapters. In subsequent chapters, literature will be included as a source of data, because in grounded theory, literature is considered to be a *slice of data* (Glaser and Strauss 1967, p65). Relevant literature and significant theories that inform and are important to the theorising of this grounded theory study are woven into the discussion throughout the thesis. The relevant literature will be compared with the data generated by other means. Thus the points of convergence and divergence with the literature, previous research and extant theories are discussed in the context of the research findings (Charmaz 2006, p166).

The methods used in identifying literature for this review

The method used for identifying literature for this research included an initial ‘snowball’ approach where works relevant to the broad research topic were sourced, and references cited in these works accessed. Primary source materials were also accessed through major electronic bibliographic databases including CINAHL, Web of Science, Medline and PsychINFO. There was a major focus on nursing literature, because the research is situated within that discipline. However, the importance of other disciplines, such as sociology were recognised as essential to informing this work. Key words used in the searches included child*; hospital*; child centred care; and research + children. Policies and reports relevant to the study were also a vital source of information. The areas of focus related to research around children’s experiences, family and child-centred care and recommendations around children’s healthcare.

Children’s healthcare and research with children reflect society’s positioning of children

The chapter highlights some of the ideas, myths, rhetoric and customs that surround children’s place in society. In doing so, it establishes that present and evolving attitudes and practices in the healthcare and hospitalisation of children reflect and have their origins in the changing ideologies of childhood and children’s status in the wider social world (Hogan 2005, p29). Few historical works have included children in their telling and children have an apparent silence and powerlessness in historical works. Children’s perspectives have not been present and so the interests of children have not always been at the fore (Hendrick 2008, p42). Instead, children’s interests have been subservient to the interests of others, including those of adults and institutions.

The first part of this review examines society’s evolving view of children and childhood. Secondly, children’s healthcare and hospitalisation are examined and positions of the past are seen to resonate with more recent stances in the care of children in hospital. Thirdly, a review of the philosophies that underpin paediatric nursing serves to illustrate changes in care practices for hospitalised children. These areas of analysis provide the context for a study of children’s experiences and perceptions when they undergo surgery.

A history of childhood and children's status

The notion of children as individuals and of childhood as a concept is an important one. It seems that ideas from the past about childhood exist, but the lives of children are more difficult to locate (Cunningham 2005, p2). Changes in children's status in western society reflect the changing views toward children and the needs of children and families. Social, economic, demographic and political factors have influenced the experience of children and childhood, as they have become increasingly separate to adults and adulthood (Cunningham 2005, p3).

Children's position prior to the 19th century

One of initial debates about childhood was presented in a well-documented history of children and childhood by Aries (1962) in the publication *Centuries of Childhood*. The view that childhood should be seen as a social construct, and that this construct of childhood was subject to historical change was influenced by Aries' work. In seeking to understand the place of children in contemporary times, Aries (1962) compared their place with the position of children in the past. According to Aries (1962), in Western European history during the Middle Ages, there was a trend to recognise just two stages of development, infancy and adulthood, and there was little concept of 'childhood' (p125). But Aries (1962) also stated that did 'not suggest that children were neglected, forsaken or despised' (p125), rather that there was little to distinguish the child from the adult. Once over the age of seven years, an individual was considered old enough to be physically independent of their parents, and able to contribute as a fully functioning member of adult society. Education for girls up to 12 years and boys to 14 years (the time of puberty) in this period did not mean school, but the gradual initiation to adult work (Cunningham 2005, p31).

In the 18th century society, children were beginning to be recognised as valuable and vulnerable property, and childhood was coming to be recognised as a stage of life that was to be valued in its own right (Cunningham 2005, p59). The work of Locke and Rousseau portrayed children as individuals and impacted on subsequent views of childhood. Whilst this had an influence on the way children came to be viewed by society, their works also influenced the views that children were unformed or 'becoming' persons, passive and dependant (Hogan 2005, p30).

Children, as well as slaves and animals were the focus for humanitarianism efforts that were in part a feature of this period. However, this was also the period of the Industrial Revolution and the work potential of children was far too valuable to be lost to employers or the state (Kociumbas 1997, p28).

Children and the 19th century

In Britain, the Royal Society for the Prevention of Cruelty to Animals was formed in the 1820s, whereas the National Society for the Prevention of Cruelty to Children was not founded until the 1880s. In a letter to an English newspaper in 1881, a correspondent asked: ‘whilst we have a Society for the Prevention of Cruelty to Animals, can we not do something to prevent cruelty to children?’ (cited in National Society for the Prevention of Cruelty to Children 2009).

In Australia juvenile convicts were subject to significant physical and sexual abuse and the forced separation of indigenous children from their families became official government policy that continued well into the 20th century. The effects on the ‘stolen generations’ was profound, and impacted on individuals, families and communities.

Yet, the 19th century is described as the age of Enlightenment and during this period, society became increasingly aware of its responsibilities for the welfare of children. In the 19th century, children were viewed as separate to adults, as a special and vulnerable class in need of protection. A number of pieces of legislation were enacted in Britain to protect children from practices that caused them significant harm. These included The Chimney Sweeps Act of 1840, banning the use of children as chimney sweeps. The Mines Act, passed in 1842, forbade the employment of women, girls and boys younger than 10 years underground. The Education Act, 1870, legislated for the universal education for children (Lansdown 1996) and in segregating children and the adult world of work, schools became central in constructing a new image of childhood (Das Gupta 1994, p10).

The century of the child

The next century will be the century of the child, just as much as this century has been the women's century. When the child gets his rights, morality will be perfected (from the drama *The Lion's Whelp*, Cunningham 2005, p171).²

During the 20th century, there were significant shifts in the political, educational and social opinions regarding children's health, welfare and education. The views of children and childhood were influenced by developments including the emancipation of women, shifts in economic infrastructure of family life and by the shifting focus of research on children. By the century's end, children had acquired rights that were not foreseen at the century's beginning (Cunningham 2005, p203).

For much of the first half of the 20th century, however, the tone of advice literature for parenting of children was influenced by the science of behaviourism – the belief that desired behaviours can be achieved by training children with rewards and punishments (Greig et al. 2007, p24). Professionals involved in the care of children including physicians, social workers, child psychologists, and teachers increasingly drew upon the expertise of developmental psychologists to guide child care practices. Calls for new structures of knowledge for understanding and managing childhood resulted in advice to parents on caring for their children. An example is advice of American psychologist J.B Watson (1928) presented here:

Even granting that the mother thinks she kisses the child for the perfectly logical reason of implanting the proper amount of affection and kindness in it, does she succeed? The fact that... we rarely see a happy child is proof to the contrary. The fact that our children are always crying and always whining shows the unhappy, unwholesome state they are in. Their digestion is interfered with and probably their whole glandular system is deranged. There is a sensible way of treating children. Treat them as though they were young adults. Let your behaviour always be objective and kindly firm. Never hug or kiss them, never let them sit on your lap. If you must, kiss them once on the forehead when you say goodnight. Shake hands with them in the morning. Give them a pat on the head if they make an extraordinary good job of a difficult task. Try it out. In a week's time you will find how easy it is to be perfectly objective with your child and at the same time kindly (cited in Hughes 1999, p15).

² The book *The Century of the Child* was published by feminist Ellen Key in 1900 – the idea for the title of the book came from the drama *The Lion's Whelp*.

The attempt to make parent – child interactions a science encouraged a distancing between parent and child. Watson’s call for children to be treated ‘sensibly’ and ‘objectively’ is evidence of this view of child rearing.

‘The parlous state of childhood – in the 21st century’³

Reflecting on the UN Convention and the development of children’s rights and children’s position in society in the 20th century, Carol Bellamy, Executive Director, United Nations Children’s Fund (UNICEF) stated: ‘A century that began with children having virtually no rights is ending with children having the most powerful legal instrument that not only recognizes but protects their human rights’ (UNICEF 2004).

Societal and economic impacts provide varying contexts for children’s lives in the 21st century. For example, women’s increased participation in the workforce (Christensen and Prout 2005, p52) and changes to family structures (including the increasing numbers of single parent families, and of childless families) impact on children within families and children in broader society. Intergenerational relationships are also considerations. As well as care for children, care for increasing numbers of older adults in our community is an issue for families and for society (Christensen and Prout 2005, p51). Recent social phenomena impacting on children include their exclusion from public spaces and changes in play, activity and diet (Darbyshire et al. 2005, p418; Christensen and Prout 2005, p53).

In summary, children’s positioning in society has undergone change that parallels society’s views of children, as well as political and economic drivers. Children’s rights to participation in matters of concern for them are recognised internationally, yet the translation of this recognition into practice still has some way to go. The next sections consider medical and nursing care of children.

³ A quote from the article Christine, J. (2009) Fragile: do not expose to life. In *The Weekend Australian Magazine* News Limited, Sydney, pp. 13-17. 3-4 October.

Medical care of children

If we take a survey of the different provinces of medicine, we shall readily discover that one happens to be of the greatest consequence to society... I mean that which regards the diseases of infants, has hitherto lain uncultivated, or at least been much neglected... I am told there are physicians of note here, who make no scruple to assert, that there is nothing to be done for children when they are ill (Armstrong, 1783, cited in Dunn 2002, p228).

Areas of study and interest around children's health for health professions including medicine, nursing and allied health have been sensitive to and responsive to social, political and economic factors of the times (Mayall 1996, p23). The history of paediatric care in Australia has its roots in the development of the specialty of paediatrics in Western Europe, and is particularly influenced by British history. Therefore this part of the review draws heavily on the care of children that focuses on the British perspective.

The first institutions for the care of children were most likely foundling asylums, and the earliest of these was established in 8th century Milan. The establishment of these institutions were society's response to the large numbers of children who were left abandoned by families. The foundling asylums had very high mortality rates (almost total in some) due to lack of staff, poor hygiene, inadequate diet, infection and the lack of medical knowledge of the times (Lansdown 1996, p1).

In the 1500s, society was just beginning to consider the nature of the 'child' and the first English paediatric medical text *The Book of Children* was written by Thomas Phayre in 1554 (Lansdown 1996, p2). In this era, infant mortality rates were high because of poor hygiene, war and infectious diseases, and there was a significant lack of medical treatment specific for children (Lansdown 1996, p4). 'All mine died in infancy' wrote Renaissance author Montaigne (cited in Aries 1962, p37).

The British physician, Dr George Armstrong, established the Dispensary for Infant Poor in 1769. At the time, records showed that between a quarter and a half of all infants died within their first year. In 1772, the Friends to Armstrong's Charity suggested the establishment of a children's hospital: 'A house fitted up for the reception of such Infants as are very ill' (Lansdown 1996, p6). In reply, Armstrong (1777) stated 'If you take away a sick child from its Parent or Nurse you break its Heart immediately' (cited in Lansdown 1996, p6). Armstrong's celebrated statement

regarding the separation of the mother and sick child resonate with the philosophies of care in the more contemporary history of the hospitalisation of children. However, Armstrong was also of the view that the parent should not be with the sick child in hospital, for 'Would not the Mothers or Nurses be perpetually at Variance with one another if there were such a Number of them together?' (cited in Lansdown 1996, p6). Once again Armstrong's words can be seen to resonate with voices of the present. Contemporary studies about the relationships between parents of hospitalised children and health professionals identify continuing tensions for both parents and nurses, see for example work by Darbyshire (1994); Rowe (1996); Macnab, Theissen and McLeod (2000); Coyne (2003); Franck and Callery (2004) and Shields, Pratt and Hunter (2006).

In the 1700s, children were rarely admitted to hospital. Those who were admitted were initially placed on wards with female patients, with the understanding and intention that the women would provide care to the children.

Another advantage attending this charitable institution is, its being confined to children only, whereby their complaints are more closely attended to, and considered; for when sick children are admitted promiscuously with adults, the former never have so much attention paid them as the latter (Armstrong, 1793, cited in Dunn 2002, p230).

Again there a strong parallels between Armstrong's statement in 1783 and the circumstances of the present. More than two hundred years later, in 1992, Professor Beveridge commented at the coronial inquiry into the death of a six year old child following tonsillectomy in New South Wales. Professor Beveridge stated that when children are cared for alongside adults 'children always come off second best' (cited in Hancock 2003). The *Platt Report* (1959); the Kennedy Report into the Bristol Infirmary (2001) and the *Garling Report* (2008) have all similarly found that children's needs are best served in dedicated paediatric settings where children are cared for by paediatric trained staff.

On the numbers of children Armstrong treated, the following record relates to children who had whooping cough:

From the time of the first institution of the Dispensary for the Infant Poor, which was on April 24th, 1769, till the beginning of June 1777, I had seven

hundred and thirty-two poor children, ill of the Hooping-Cough, under my care; out of which number have died twenty-five (Dunn 2002, p229).

As well as whooping cough, other conditions Armstrong wrote of included: ‘thrush, watery gripes, convulsions, hydrocephalus, teething, hectic fever, measles, smallpox, eye problems, rickets, worms and scrofula [a form of Tuberculosis]’ (Dunn 2002, p229).

19th century health care for children

In Britain prior to the mid-19th century, sick children were generally cared for in their own homes by family members and friends and dispensaries provided advice and medicine to parents of sick children (Darbyshire 1994, p2, Kristensson-Hallström 2000, p1021). The treatment of childhood conditions was vigorous, with the aim to rid the body of humours and purify the blood. Opium was commonly used to treat children for a wide range of conditions including teething, worms and diarrhoea. Croup was commonly treated by ‘bleeding the child to syncope and then applying leeches to the trachea’ (Mahnke 2000, p708).

Around this time in Britain, there was significant opposition to the establishment of a dedicated children’s hospital, as medical staff and lay people were of the opinion that children were not suitable objects for hospital treatment. This is in contrast to Europe where children’s hospitals were already well established. Whilst Florence Nightingale (1859) was not supportive of a dedicated children’s hospital, she wrote of the ‘vital importance of the careful nursing of children’ and their special nursing care needs in *Notes on Nursing*:

To revert to children. They are much more susceptible than grown people to all noxious influences. They are affected by the same things, but much more quickly and seriously (p128).

Against this opposition, the children’s hospital, Great Ormond Street opened in London in 1852. However, infants under 2 years were not initially admitted to this institution and children ‘suffering from accidents or external injuries or their immediate effects’ were not eligible for admission (Cunningham 2005, p175). This was because early hospitals were largely isolation hospitals, and it was not until toward the end of the century that there was a shift toward a role in providing therapy. Hospital stays could last months, and sometimes years. Surgery was not

considered an important activity of the early children's hospitals. The understandings of the time were that 'there were no surgical problems in childhood demanding special skills or study' (Higgins, 1952, cited in Lansdown 1996).

In Australia, during the 1840s, child mortality rates were lower than those of England and this is because of the lesser numbers of children in the community. Health problems of children in early Sydney resulted from epidemics, including typhoid, dysentery, influenza, measles, mumps, diphtheria, scarlet fever and whooping cough. Other common childhood sicknesses included scurvy, eye infections and sexually transmitted diseases (Fabian and Loh 1989, p36). The following treatment was prescribed by a Dr Black of Penrith in 1834 for an ailing infant:

Keep applying enemata composed of two desert spoons of turpentine mixed with the yolk of an egg and three tablespoons of warm water. Administer five grams of finely ground aloes, two of calomel and three of ginger by mouth...mix an ounce of the tincture of soap with one drachma of tincture of opium, and rub a teaspoon of this mixture on the infant's stomach morning and evening (cited in Kociumbas 1997, p66).

The therapeutic effects of this treatment can only be guessed at.

Melbourne's Hospital for Sick Children opened in 1870 and was the first paediatric hospital in Australia, and the Children's Hospital in Sydney was established in 1880 (Fabian and Loh 1989, p98). With the commencement of the 20th century in Australia, infant mortality rates had increased significantly and exceeded 100 deaths in every thousand and almost another 100 died before their fifth birthday (Kociumbas 1997, p96). Infectious diseases such as tuberculosis, cholera, typhoid and diphtheria were common, and spread readily through communities, sometimes resulting in the death of several members of a family within days or weeks of one another (Greig et al. 2007, p14). But these rates decreased considerably in the early 20th century. This was not so much through improvements in the treatment of diseases, but rather to disease prevention and improvements in public health through clean water supplies, sanitation and supervision of dairy practices (Kociumbas 1997, p151).

20th century child healthcare

Parents came to be excluded from caring for their hospitalised child, and parents are notable by their absence in the excerpt describing a children's ward presented in the introductory chapter. Developments such as increasing professionalisation of medicine and nursing, developments in anaesthesia and antisepsis influenced the traditional model of care. They also served to reinforce the exclusion of families in participating in decision making and involvement in the child's care. The understandings of the time were that children in hospital settled better when parents did not visit for it was observed that children would cry following a visit from their parents. When parents did not visit, children were initially distressed, but they were seen to settle quickly, and they remained compliant and quiet for the remainder of their time in hospital (Lansdown 1996, p17). The strong emotional reactions of children to their parent's visits were considered by healthcarers as evidence that these visits had a detrimental effect on the children's wellbeing. This situation was also in keeping with the social view of children of the time – children were valued, but were rarely seen and were not heard. However, in acting in this way, health carers believed they were indeed serving the interests of the child.

Changes in this practice were slow and even in contemporary paediatric care parents may be excluded from some areas children are cared for, for example recovery rooms. An innovative Mother and Baby Unit where mothers were able to stay with their hospitalised baby was established by James Spence (1947) in Glasgow in 1920:

The mother lives in the same room with her child... She feeds the child; she tends the child; she keeps it in its most comfortable posture, whether on its pillow or on her knee. The sister and nurse are at hand to help and administer technical treatment to the child (p129).

Benefits to the child, the mother and also benefits to nurses were described.

According to Spence (1947), nurses could 'learn much... not only about handling a child but about life itself' (p129). Portentously, Spence (1947) claimed 'Apart from all other reasons, the shortage of nurses will impose this method on us in the future' (p129). Thus forewarning the current shortage of nurses internationally as well as increasing expectations for parents to provide care for their hospitalised child (Shields et al. 2006).

Another centre that introduced innovative care practices for hospitalised children was in New Zealand in the 1950s where Drs Cecily and H.P Pickerill admitted mothers with their children who were to undergo plastic surgery. 'Done principally to prevent cross-infection, in which it has been wholly successful, it has had great value for both mothers and babies' (Bowlby 1965, p177-8). These units were noteworthy for their focus on the importance of the role of the family in caring for the child who required hospitalisation.

In general, Australian children's health status in the 21st century is relatively high when compared to other age groups and international comparisons, with the exception of poorer health among indigenous children (Queensland Health 2002). The current situation sees increasing specialisation within the specialty of paediatrics; shorter hospital stays; increased day of surgery admissions; and advances in technology and treatments, for example in the areas of paediatric oncology and transplantation. When compared to adults, children experience less frequent in-patient services and shorter hospital stays. This is counterbalanced by children's increased dependence and the intensity of the care that they require, which also increases the cost of their care (Hanson et al. 1998, p39). Services for children offered by specialist children's hospitals and children's wards in general hospitals can include emergency departments, specialist inpatient, ambulatory care and rehabilitation services for children with acute illness, chronic illness and disability.

Children in hospital: from bureaucratic interests to the interests of families and of children themselves

The increasing recognition that the interests of children and families should be at the centre of children's health care has been slow to develop. This requirement for children's care has been even slower to become embedded in paediatric practice and institutional interests have held prominence. The tensions between economic and bureaucratic concerns versus what is known to be in the best interests of the child and family continue into the 21st century.

The harmful effects of children's separation from their parents

Studies of separation and attachment have had a profound influence on the way infants and children are cared for in hospitals. The development of hospital policies

and practices that support the care of children in the context of the family is in part a direct result of this influence.

The Second World War caused dislocation of many families and child psychoanalysts Anna Freud and Dorothy Burlingham explored the effect of separation of children from their parents as a result of the war (Shields and Nixon 1998). The work of these investigators influenced that of James Robertson and John Bowlby on the effects of separation of mother and child.

Bowlby and Robertson (Bowlby 1959) described theories of attachment, separation and loss in hospitalised children or children in care. Bowlby's (1959) theory of attachment recognises the infant's emotional tie to the primary caregiver. An attachment is an emotional bond in which the person feels secure and the other person presents a safe base from which to explore the world. The quality of the infant's emotional tie to the caregiver has profound implications for the child's feelings of security and their capacity to form trusting relationships, as described by Bowlby (1952):

the prolonged deprivation of the young child of maternal care may have grave and far-reaching effects on his character and so on the whole of his future life (p46).

With increasing age, the child depends less on the close physical proximity of the parent and relies more on a confidence that they will be there and responsive in times of need. Children construct a continuing bond that they use as a secure base in the parents' absence. The child has a set of expectations, or an internal working model, about the availability of attachment figures and their reliance on them for providing support during periods of stress. This model also becomes a part of the child's personality and serves as a guide for all future relationships (Berk 2006, Bowlby 1965).

Separation or the breaking of the attachment bond could present danger to the psychological well being of the child and if the separation were to become permanent, the child will grieve for the loss. With Robertson, Bowlby (1965) described the three stages of grieving as protest, despair and detachment and this work had significant influence on understandings of children in care. Protest is

characterised by crying and acute distress when the mother is lost to the child and the child tries to recapture her. Despair is characterised by increasing hopelessness, withdrawal and less efforts to be reunited with the mother. Detachment describes the child's behaviour of 'settling down' in the 'separation environment', where the child displays marked loss of attachment behaviours to the mother on her return (p214).

Bowlby and Robertson (1965) presented several studies that described the effects of separation from family on children. One study described protest behaviour in children admitted to hospital for tonsillectomy. The behaviour was found to be due to separation from parents rather than the effects of the operation or anaesthetic. Another study observed reactions to hospital in children between two and twelve years and found that although children between two and four years had most significant disturbance, all children showed some level of disturbance (p214).

Children require a supportive environment to cope with their hospitalisation

British paediatrician and psychoanalyst D.W. Winnicott described the effects of hospital stays on the psychological development of children and found that when children are hospitalised, they require a supportive environment that he termed a 'holding environment'. Winnicott (1965) wrote of the care of the child in health and in crisis, observing that when the child is ill 'then there is a crisis' (p72). The holding environment enables the child to move through the crisis that illness presents and to return to physical and emotional wellbeing.

According to Winnicott (1971), the child's general physical and emotional growth is dependent upon a facilitating, holding environment. The holding environment described the requirements for infants to grow and develop:

We know that it does matter how a baby is held and handled, that it matters who it is caring for the baby, and whether this is in fact the mother or someone else. In our theory of child care, continuity of care has become a central feature of the concept of the facilitating environment, and we see that by this continuity of environmental provision, and only by this, the new baby in dependence may have a continuity in the line of his or her life, not a pattern of reacting to the unpredictable and for ever starting again (p141).

Initially, holding consists of the mother's behaviour of making the totally dependent infant safe. Winnicott (1965) used the phrase 'good enough mothering' where the

mother is able to meet the needs of her infant (p57). Good enough mothering entails physically holding infants and it is from the experience of being held that the infant develops an identity - the developing child is 'held' first of all literally by the mother and later by the quality of its participation with the environment. According to Winnicott (1965), the term 'holding' represents 'not only the actual physical holding of the infant, but also the total environmental provision... in other words, it refers to a three-dimensional or space relationship with time gradually added' (p43). The holding environment is the necessary environment for the child to develop true personhood. The infant's experience of a protective space allows them to safely examine and interact with the things their world presents, even when they are frightened or alarmed, and temporarily need to retreat to a safe place (Kahn 2001, p262). Winnicott (1969) provided the following example:

A child is playing in the garden. An aeroplane flies low overhead. This can be hurtful even to an adult... What is valuable is that you hold the child close to yourself, and the child uses the fact that you are not scared beyond recovery, and is soon off and away, playing again (cited in Davis and Wallbridge 1981, p101).

When provided with the appropriate environment, the infant has the conditions needed to develop their innate potential.

Whilst based in infancy, Winnicott's theories of development and holding also continue to be integral to the growing child, adolescent and the adult. The dependable meeting of the infant's physical needs, and later, the meeting of the child's psychological needs provides them with a way to develop and to meet the challenges they are presented with. At every stage, the child's growth is affected by the quality of the environment that supports his or her development (Van Buskirk and McGrath 1999, p808).

Providing for the child is therefore a matter of providing the environment that facilitates individual mental health and emotional development... Emotional development takes place in the individual child if good-enough conditions are provided, and the drive to development comes from within the child. The forces towards living, towards integration of the personality, towards independence, are immensely strong, and with good-enough conditions the child makes progress (Winnicott 1965, p65).

Winnicott extended the holding environment from the family, to society, and to the tasks of social work and to the therapeutic relationship between therapist and patient. The concept has also been applied to various other types of settings, including residential units, mentoring and organisations (Kahn 2001, p263). The extension of the concept of the holding environment to other settings means that people in these settings who are anxious or struggling are caught up and secured by others – calmed, appreciated, understood and helped – until they are able to regain their equilibrium and continue on their way (Kahn 2001, p263).

To summarise, it has been recognised that the negative effects of hospitalisation on children can be reduced by recognition that children require additional security and support mechanisms to cope with illness and hospitalisation. Of course, parental presence is one of the most important aspects of this. These notions have had significant impacts on the philosophies of care underpinning paediatric nursing practices, and this aspect of children's hospitalisation is addressed in the next section.

Nursing care of children

I recall at one time children were well behaved, they were tied into their beds, so that busy nurses could keep track of them. There was order in the wards. Parents gave their child to the hospital to be treated (anonymous senior nurse, 1995, cited in Wood 2008, p119-120).

Just as changes in society's view of children and childhood influence the medical care of children, they have also influenced models of care that underpin paediatric nursing practices. Nurse-parent-child relationships have undergone changes since children were first admitted to hospitals and these relationships continue to undergo change. Parents' participation in their children's care has been limited for those reasons provided previously (p32), as well as by the military influence associated with the Nightingale tradition of nursing. Rules for limiting parent's visiting their hospitalised children in 1947 are not dissimilar to those for visiting prison inmates:

Patients are not allowed visitors unless they have been in the hospital for a period of four weeks, after which time only the parents or guardians (no friends or relatives are allowed) are permitted to visit on each alternate Sunday in each month, between the hours of 2 p.m. and 3.30 p.m. Parents or

guardians of patients dangerously ill are allowed to visit as often as the Doctors consider necessary.

Parents or guardians of patients in the Baby Wards and Infectious Wards are only allowed to visit with the special permission of the Medical Superintendant or his Deputy.

These regulations apply to the hospital section... and have been made to protect the interests of the patients in the Hospital...

Lollies, Cakes, Biscuits, etc., must not be brought to the Hospital for patients. Raw or dried fruits, nuts, eggs and nourishing foods are of benefit, but must be handed to the Sister of the Ward (Royal Children's Hospital, cited in Street 1992, p11).

These regulations espoused to safeguard the best interests of the ill child. Street (1992) argues however such practices did not support the interests of the parent or child so much as institutional interests (p11). For example, medical staff determined how often, and for how long, children might be with their parents. The recognition that such care practices could cause possible psychological trauma to children who experienced hospitalisation was slow to develop.

Correspondence from Bowlby (1940) in *The Lancet* outlines the debate that occurred within the healthcare professions around children's hospitalisation.

Sir – In your leading article of Jan 27 you dealt somewhat cavalierly with the psychological case in favour of children in hospital being visited. You state that with 'few exceptions no child mopes in a children's ward,' that 'in a few days the young child, at any rate cheerfully adopts the nursing and medical staff *in loco parentis*' and finally that 'the child does not need visitors in the same way as does an adult patient.' (cited in Wood 2008, p120).

Changes to care practices came incrementally and with opposition. In Australian hospitals, daily visiting for children was adopted in the 1950s and 1960s and mothers with young children were admitted in the late 1970s (Wood 2008, p123). But nursing care of children in hospital still failed to fully respond to children's needs. The founder of AWCH, Joy Chester (1984), described her experiences around the admission to hospital of her child:

In July, 1969, my 6 year old son was hospitalised at a major children's hospital in Sydney. I stayed with him for four days. The ward TV-set proudly showed man taking his first steps on the moon, while below it, lonely babies and children cried, rocked or were quietly withdrawn. The contrast of

advanced scientific technology and the neglect of the emotional needs of those children was overwhelming (cited in Wood 2008, p124).

This part of Australian paediatric nursing history is little known beyond those people with personal experience aware of the ways children's wards operated (Wood 2008, p124). However, the deep and lasting effects of separation continued for many who were hospitalised as children.

Family centred care

Following on from, and in response to the work of individuals such as Bowlby and Robertson; reports such as the *Platt Report* (Ministry of Health 1959) and consumer organizations such as (the British) Action for Sick Children, and AWCH; the second half of the 20th century did see a transformation in care practices. The philosophy of family centred care intended a more equal partnership between nurse and parent in the care of the hospitalised child. The philosophy of family centred care 'recognises that the family is central in a child's life and should be central in the child's plan of care... The philosophy of family-centred care calls for partnerships between parents and professionals' (Ahmann 1994, p113). In the transition toward the paradigm of family centred care, various models of care recognising the family's involvement evolved. These include 'partnership in care', 'care by parent' and 'hospital in the home'.

The involvement of parents in the care of their sick child became an accepted feature of paediatric nursing in the 1980s and 1990s and parent participation in the care of children in hospital is acknowledged as a fundamental aspect of paediatric nursing (Power and Franck 2008, p623, Casey 1988, p8). The philosophy of care however has had complex issues associated with it and has not been considered aproblematic. For example, Darbyshire's (1994) work explored the lived experience of parents who lived in with their hospitalised children. Darbyshire's important work illuminated and revealed the complexities and the discordances between parents' and nurses' understandings and expectations in relation to parent participation. Darbyshire found that parent participation was not so much a philosophy underpinning practice but an unspoken and haphazard arrangement between parent and nurse.

Research indicates that parents in general both want to, and expect to, participate in their child's hospital care. However, the level to which they want to be involved may

differ. Most recent studies indicate that the level of parental involvement has extended from undertaking activities of living they would normally perform for their child at home to include more complex responsibilities such as monitoring and coordination roles. Further, the attitudes and activities of healthcare professionals can both facilitate and hinder parent participation (Power and Franck 2008, p636). There is evidence that parents in contemporary paediatric settings are feeling increasing pressure to participate in their children's care. This is seen to coincide with an increasing expectation by nurses who take parent's participation for granted (Shields et al. 2006, Coyne and Cowley 2007). The increased involvement of parents in their child's care is reminiscent of practices of the past. It also seems that the increasing expectation on parents is to some extent resented by them (Power and Franck 2008, p637). This may be an indication that institutional interests have taken precedence and that practices may be not supportive of the needs of families.

A meta-analysis of qualitative studies on family centred care sought to identify those studies that actively involved the family and/or child in the planning and /or delivery of children's healthcare during their hospitalisation (Shields et al. 2006). The review found 11 studies met the criteria for inclusion in the meta-analysis and the studies identified included parents, nurses and other healthcare professionals as participants. It is important to note that none of these studies included children as participants. Although there are numerous studies that have explored the concept of family centred care and its application in practice, little attention has been paid to children's views of this matter that is of course, a central concern for *them*. The recognised members of the partnership when family centred care is practised, are the health professional and the parents, or carers. In a family centred care partnership, the child is allocated a passive role.

Child centred care

Child centred care is a more recent paradigm of care that has emerged and, as the name suggests, focuses on the child. In contrast to family centred care, in child centred care, the child is considered a key member of the partnership, and the child is considered and listened to first and foremost. The British report *Getting the Right Start* (2003) describes child centred hospital services:

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 the illness or injury, and the treatment they need. They should be encouraged to be active partners in decisions about their health and care, and, where possible, be able to exercise choice (Department of Health 2003, p9).

Underpinning the philosophy of child-centred care is the premise that the best interests of the child must be the paramount consideration. Further, health care providers should approach children as individual people with their own needs and rights to privacy and dignity, involving them in decisions affecting their care (Southall et al. 2000). Examples of ways hospital services can be child centred include the following:

- Consider the ‘whole child’, not simply the illness being treated
- Treat children as children, and young people as young people
- Be concerned with the overall experience of the child and family
- Treat children, young people and parents as partners in care
- Integrate and co-ordinate services around the child and family’s particular needs
- Graduate smoothly into adult services at the right time
- Work in partnership with children, young people, and parents to plan and shape services and to develop the workforce (Department of Health 2003, p9).

This philosophy of care is congruent with the increasing recognition of children’s rights as expressed in the UNCRC (UN 1989) and health care policies such as the World Health Organisation’s Child Friendly Healthcare Initiative (Southall et al. 2000, p1060). Whilst doing so, the philosophy still recognises the central role of parents and families in the relationships and interactions with healthcare professionals.

There are increasing references to this paradigm of care within the paediatric nursing literature. References to provision of child centred health services and child centred care are found in the Bristol Royal Infirmary Inquiry (2001) and in commentaries since that inquiry. Callery (2001, p3) and Glasper (2003, p3) claim that this interest

is at least in part a direct result of the events that led up to the inquiry. The Bristol Inquiry found some 30 to 35 deaths of children undergoing cardiac surgery between 1991 and 1995 were a result of ‘flaws and failures ... within the hospital, its organization and culture’ (Kennedy 2001, p154).

Just as the *Platt Report* (Ministry of Health 1959) found policies and practices served the interests of the institution rather than the child or parents, the Bristol Inquiry found that the interests of the child and parents continued to be subservient to systemic and institutional interests. The *Bristol Inquiry Report*, also known as the *Kennedy Report*, observed that children’s rights and vulnerability were overlooked; that quality of care was less than adequate; that services were fragmented; and that there was an absence of open and honest relationships with children and parents as partners in care (Kennedy 2001). The *Bristol Inquiry Report*, made reference to the *Platt Report* (1959), as well as reports subsequent to the *Platt Report*. All the reports advocated for the needs of children and their parents to be central in informing children’s healthcare provision. However, healthcare practices had failed to respond accordingly:

Remarkably, some would say scandalously, despite the consistency of these recommendations over such a long period of time, there has been an equally consistent failure fully to implement these fundamental principles, a failure which continues to this day (Kennedy 2001, p417).

In the report, Professor Kennedy (2001) found services treated children as mini-adults, simply needing ‘smaller beds and smaller portions of food’ and that information was not provided in a suitable form for children or parents. Further, staff did not have specific training in caring for children and that facilities were not appropriate for the special needs of small children, older children, adolescents and parents (p12). One of the major recommendations from the report was for children in hospital to be ‘cared for in a child-centred environment, by staff trained in caring for children and in facilities appropriate to their needs’ (p2).

The perception that children require less expert, or less numbers of staff was critiqued by (paediatrician) Professor Baum at the inquiry:

It is manifestly the case that children should be looked after by children-trained staff...we have to break through barriers of small people needing

fewer staff to the understanding that these whole-time people, these children and babies, who require whole-time staff and the sicker they are, the more complex the health care techniques, the more dedicated preoccupied attention [is needed] from the nursing staff attending (cited in Kennedy 2001, p429).

The shortage of nurses with specialist qualifications in paediatrics is a component of the wider shortage of nurses internationally. The shortage of qualified children's nurses presents the risk that children will not receive care appropriate to their needs.

The findings from the Bristol Inquiry indicate that care of children in UK hospitals has still some way to go toward meeting the needs of children and their families, so they are placed at the centre of care, and included in care decisions. The findings may well apply in other settings, such as Australia, and the *Garling Report* (2008) indicates that this is indeed the case. The recommendations within the literature are for those caring for children to have a good understanding of children's healthcare needs as well as their physiological, psychological, intellectual and emotional development (Kennedy 2001, p429). The special considerations that are required in relation to children's developmental needs means that adult approaches are not suitable but also that different approaches are required for children of different ages:

They experience and see the world differently. Children are in a constant state of growth and development which creates particular needs and demands which are of a different order from those affecting adult patients... Children communicate their thoughts and feelings in a very different way from adults (Kennedy 2001, p419).

Whilst there is acknowledgement for child centred practices to inform children's healthcare in order for children's needs to be served, child centred care is not yet fully embedded in practice.

Conclusion

This part of the literature review has considered children's place in society and in healthcare. Societal attitudes influence and impact on children in general, and their healthcare. This gives context to the current study that explores children's admission for surgery. In much of the published historical works children have been denied a voice. It is not easy to discover children's own views on their lives in those works and children have not been readily visible as historical actors (Hendrick 2008, p42).

Without a voice, children's perspectives are rarely presented, adult perspectives remain the norm and therefore understandings remain incomplete.

Parent's participation in their child's healthcare has been advocated for a number of decades. More recently, and in still limited ways, children themselves are being included as active participants in their care and decision making processes relating to care. Children are also being given an increasing voice in policy development.

However, there remains work to be done in this area so that children can be involved as full participants. The aim of this study was to explore children's own perspectives of their admission to hospital and surgery. In doing so, the research answers the call for children's perspectives to be given voice in matters of concern to them.

The next chapter outlines the place of children in research.

Chapter 3: Locating children in research

By failing to listen to children, the adult world can be blind to the reality of children's vulnerability to harm. Adults cannot protect children without understanding their experiences (Lansdown 2006, cited in Graham and Fitzgerald 2010, p9).

An understanding of children's role in research provides a context for some of the methodological and ethical considerations that are present for research that includes children as participants. This study recognises that in order for healthcare to meet children's needs, children need to be consulted and included as active participants in research that is respectful of them and that protects their interests.

In this chapter, children's role in research is considered, as of course, this is a central aspect of this project that has children as participants. Children's age, understandings cognitive abilities and experience, and the associated ethical implications are considered. Ethics forms part of the discussion in this review and was a central aspect of the research project as a whole. Finally, the appropriateness of grounded theory as the approach for the research is determined.

Research that includes children as participants is a relatively recent area of inquiry, and reflects past social constructions of childhood as well as the influence of the changing views of the present. Just as the status, roles and rights that children have in society has changed over time, so has there been a change in the positioning of children in research (Woodhead and Faulkner 2008, p12). The following section traces the role children have had in research, and highlights the shift in focus from children as objects of research toward the view of children as active agents in the research process. There has also been a shift in focus from considering how adults see children, to an increasing focus on how children see their world; for children have a perspective of their own and their own strategies for dealing with the social world that they perceive (James et al. 1998, p182). Yet children's voices are still poorly represented even though the importance of their presence is now acknowledged and well supported by government policy and underpinned by the UNCRC (Battrick and Glasper 2004, p329).

A key issue is that when children are viewed as objects in research, rather than as active participants, there is increased risk that they will suffer harm. Reviewing the harmful effects of research on children provides a warning of the potential for future harm to them through their participation, and this aspect of research with children is where the discussion begins.

Human research in general has contributed enormously to human good and the vast majority of research in Australia has been conducted in a safe and ethical manner (National Health and Medical Research Council (NHMRC) 2007, p3). However, in respect to research with children, it must be acknowledged that some research undertaken in the pursuit of increased knowledge has been unfortunate in terms of the effects the research has had on the children involved. Some examples of research from the past that involved children follow.

Children as objects in research and possible harm to them

Edward Jenner's celebrated research in the late 1700s was to find vaccinations against potentially fatal diseases, including smallpox. In the course of the work Jenner conducted a number of experiments on his infant son. After inoculating his son with swinepox, Jenner tried several times to deliberately infect the infant with the smallpox virus (Mahnke 2000, p708). Jenner's work influenced the development of medical science and immunisation, however the risks his son were exposed to were significant and such research would not meet current ethical standards.

During the 19th century, experiments were common with institutionalised children, as institutions conveniently provided a captive subject pool and controlled conditions. In some instances, institutionalised children were intentionally infected with diseases including leprosy, syphilis, gonorrhoea and tuberculosis in order to study diagnostic tests and vaccines (Meaux and Bell 2001, p242). For example, in 1896, hospitalised children were used to test the then experimental lumbar puncture, without parental knowledge or therapeutic rationale (Meaux and Bell 2001, p242).

During the 1930s, investigators used children in a number of trials of untested vaccines. Thousands of children were involved in trials of the live polio vaccine, and some children died as a result of their involvement in this research (Meaux and Bell 2001, p242). The Willowbrook Study was conducted on institutionalised children in

a New York state school in the 1950s and 60s (Johnson and Nelson 2000, p10). The children from this institution were injected with strains of hepatitis with the aim of developing a prophylactic agent. Some of the children were fed extracts of faeces from infected patients. The study has been strongly criticised in several areas, including its overall design and for the use of coercion and deception in enrolment processes. There was a waiting list for entry into the school, but children whose parents consented to their child's participation in this research were immediately enrolled into the school. Parents had also been given to incorrectly understand that their children were receiving a vaccine for hepatitis (Johnson and Nelson 2000, p10).

In New Zealand, vaginal swabs were taken from more than 2200 newborn female infants without parental consent from 1955-1976. This was one of the practices identified in what was described as the 'unfortunate experiment' at the National Women's Hospital in the Cervical Cancer Inquiry (Johnstone 1989). The chief investigator had lost interest in the trial after 200 babies had been swabbed. However, the routine, useless and potentially damaging swabbing continued, and a further 2000 babies were swabbed unnecessarily⁴.

In recent years, there has been public concern in Australia and abroad about the retention and use of children's organs as part of autopsy practice without parental knowledge (NHMRC 2001). It is important that the views of researchers are reconciled to the views of families. For example, researchers may view a removed organ as dead tissue to be examined for its scientific value, such as a damaged or malformed heart. Knowledge gained through such study can have important implications for improving outcomes for others. But this view is in contrast to that heart being a representation of intimate loss for parents (Fox 2007, p2641).

The studies described had the potential to, or did result in, actual harm to children and their families through their participation. If contemporary ethical principles and

⁴ The purpose of the study, conducted without consent, was to examine the natural history of carcinoma in situ of the cervix in 948 women who had abnormal cells. One group of women was treated and the other was not, despite the known risk of cancer spread. The untreated women developed the potentially fatal cancer at 25 times the rate of the treated women, and had a 12 times greater chance of dying Young, D. (2005) Will exercising informed consent stop 'unfortunate experiments'? *Birth*, **32**(1), 1-3.

values such as respect for persons, research merit and integrity, beneficence and justice were applied to these studies, they would not have been able to proceed (NHMRC 2007). When viewed with a contemporary lens, a number of studies from the past were negligent of the rights of children, insensitive to their feelings and a cause of harm to them. These activities reflect the historical and cultural contexts and some taken-for-granted assumptions of the period in which the research was conducted. Whilst the value system of the period might provide an explanation for such research, children themselves had no part in its construction. Children harshly treated by research would likely have little consolation in knowing that research was in the context of their culture (Hendrick 2008, p48).

In summary, involving children in research can have unexpected consequences that do not always result in positive outcomes for children who are involved in that process (Garden 2007, p21). This discussion has highlighted that as well as being reactive to society's problems, research activities that involve children require special considerations. In addition, there are significant differences between children and adults that need to be taken into consideration. These differences include power differentials, abilities in terms of verbal competence and the expression and understanding of abstract ideas (Hill 2005, p63). Adults have a continuing responsibility for ensuring the protection of children in research activities involving children. Responsibilities include enabling children's participation in ways that are consistent with their interests, understandings and ways of communicating (Woodhead and Faulkner 2000, p31).

Child development processes and research with children

Children's understandings and their level of cognitive development are essential considerations when children are participants in research. An understanding of the differences between adults and children is necessary, but there also needs to be an understanding that children cannot be considered as one group. This is because physical and psychological changes are numerous and occur throughout childhood.

A number of theoretical perspectives in child development can be drawn upon in research with children to assist with better understanding the nature of children and in identification of suitable research approaches (Greig et al. 2007, p19). For

example, understandings of the stages of development and of children's language development provide guides to research methods with children of different ages and cognitive and linguistic abilities. An understanding of the development of a sense of self is also important to the research process when children are participants. The following section considers children's cognitive development, with particular reference to child cognitive development theorists Jean Piaget (1896-1980) and Lev Vygotsky (1896-1934). Children's language development and the development of a sense of self, particularly as it relates to symbolic interactionism (the theoretical construct underpinning grounded theory) are considered later in this chapter.

Children's cognitive development

Cognitive development refers to the development in thought processes and mental activities including attention, memory, concept formation and problem solving (Bukatko and Daehler 2004, p271). The concept of developmental stages, linked to age and maturation form the key framework of Piaget's theories. Piaget (1950) described four stages of child development. In the sensori-motor stage, cognitive development begins with the baby's use of the senses and movements to explore the world. In the preoperational stage, these patterns develop into symbolic thinking. In the concrete operational stage, thinking becomes more organised and logical and in the formal operational stage thought becomes more complex and abstract. Piaget also argued that children are active learners whose minds consist of rich structures of knowledge.

According to Piaget's (1952) cognitive - developmental theory, children actively construct knowledge as they manipulate and explore their world. Children participating in this study were largely in the concrete operational stage described by Piaget. In this stage of development, children's thinking becomes more organised and logical compared to previous stages. However, Piaget's staged account of child development has been critiqued for limiting understandings of children's abilities and for not giving sufficient attention to the social and cultural influences on children's development. It is argued that changes in children's thinking take place more gradually than Piaget proposed. It is also argued the theory does not account for the wide variations in thinking that can exist between children of the same age that is a result of differences in children's knowledge and experiences (Berk 2006, p252).

An overall effect of the Piagetian frameworks has therefore been seen to devalue what children know and so devalue their competence (Mayall 1996, p 45). However, it is also acknowledged that Piaget held a deep respect for children and his innovative work encouraged parents, teachers and researchers to become more child-centred (Woodhead and Faulkner 2000, p25).

Research into children's experiences of healthcare has served to increase understandings of the effects of experience on children's knowledge and understanding. For example, the effects that children's previous experience of hospitalisation and medical procedures have on their level of understanding was explored in research by Crisp, Ungerer and Goodnow (1996). Further, research by Alderson (1993) found that children's understandings of their own health conditions, treatments and management were related primarily to their experience of their condition rather than age or developmental stage.

How children make sense of their world

According to Piaget (1952), children use a form of logic that reflects their experience of the world. *Schemes* are used to make sense of the world and these schemes change with age, from initial sensorimotor actions to mental representations. The processes that account for this change were termed *adaptation* and *organisation* (Piaget 1952). Adaptation involves the building of schemes through direct interaction with the environment, and consists of the complementary activities of *assimilation* and *accommodation*. Assimilation uses current schemes to interpret the external world and accommodation requires the formation of new schemes, or the modification of existing schemes, according to the external world (Piaget 1952). The new information causes the familiar to be adjusted to include the new. Organisation of schemes involves an internal process, where children rearrange and link schemes; including the new ones they have formed (Berk 2006, p221).

Piaget emphasised children as constructing their understandings of the world through *individual* activity. In contrast, the theories of the Russian psychologist Lev Vygotsky (1896-1934) emphasised the construction of knowledge through *collaborative* activity. Vygotsky placed an increased focus on the relationship of social and culturally specific practices to children's thought development than did Piaget. Children, according to Vygotsky learn from actively participating in

experiences involving them with others (Tudge and Hogan 2005, p104). They are social actors, communicators and meaning makers from the start of their lives. Language is also deemed to play an important role in this development (Vygotsky 1997). Vygotsky's theory includes consideration of both individual and interpersonal characteristics. Individual characteristics involve age, gender, temperament, motivation and prior understanding. Interpersonal characteristics involves the individual, symbolic meanings and tools and other individuals; and the broader historical and cultural contexts (Tudge and Hogan 2005, p104).

The work of Vygotsky is congruent with the current view of childhood (Hogan 2005, p33). Links can also be made between Vygotsky's work and symbolic interactionism and constructivism. Vygotsky argued that all cognitive processes, including those involved in language, arise from social interaction. The three underlying themes of Vygotsky's (1978) theory of development are the importance of culture, the central role of language and the 'zone of proximal growth or development' (ZPD) (Greig et al. 2007, p58). The notion of the ZPD is explained in more detail later in this section. According to Vygotsky (1997), development is influenced by the sociocultural context the child grows up in. Children also play an active role in their own development through their own attributes and qualities and by 'actively constructing and organising ways of thinking, feeling, communicating... to assist them in making sense of their world' (Bukatko and Daehler 2004, p7).

According to Vygotsky (1997), the culture - that is, the values, beliefs, customs and skills - of a social group are transmitted to the next generation through social interaction (p113). This occurs in cooperative dialogues between children and more knowledgeable members of the group (Berk 2006, p25). Cognitive processes appear initially on a social plane as part of the cooperative activity between the child and other. Later they appear on the psychological plane as the dialogue is internalised by the child (Greig et al. 2007, p30). Language is an important cultural tool and children then use the language within them (called private speech) to guide their thought and actions and to gain new skills (Vygotsky 1997). Like Piaget, Vygotsky thought children to be active, constructing beings, but placed less emphasis on the role of biology and children's capacity to shape their own development than some theorists (Berk 2006, p26).

Linked to Vygotsky's (1978) concept of the interpersonal characteristics and social interaction for learning is the idea of the ZPD – the learning zone in which a child can accomplish a task with the support of others. Similar to symbolic interactionism and constructivism, Vygotsky's (1978) developmental perspective is one where the child undertakes a series of transactional processes, involving the child and the environment, moving through time. The use of symbols is also a link between these theoretical constructs (Greene and Hogan 2005, p37, Vygotsky 1997). The new skills, concepts and knowledge children gain during their collaborative activities are not simply internalised as straight copies of the other persons. Instead, they are transformed by the child on the basis of the child's own individual characteristics, experiences, skills and knowledge (Tudge and Hogan 2005, p104).

In summary, cognitive development theory influences theory and research (and also practice) with children in several ways. Children think differently to adults and there are also qualitative differences in the ways that children of different ages experience and understand their world. Further, a child's learning, understanding and thinking is influenced by their social relationships, cultural influences and environmental contexts (Greig et al. 2007, p31). An understanding of these can serve as an important guide in research that includes the direct involvement of children.

Language skills and their relevance in research with children

Closely linked to children's cognitive abilities is the concept of children's linguistic abilities. Their language skills have important implications for explaining to children about research, obtaining assent as well as the questioning of children. Questioning of children (as in interviewing) involves the cognitive abilities of language, thought and memory (Greig et al. 2007, p93). There are clear differences between younger and older children in their verbal competence and capacity to express and understand abstract ideas. Having said that, however, as has been previously noted, children vary greatly at any one age, and also differ in their development between one age and another (Hill 2005, p63). Very young children, for example, have limited communicative abilities when compared to school age children. The language used with younger children needs to be suitable for their verbal understandings, and they may require more careful explanation and discussion of potential outcomes.

However, when the context allows them, many children can verbalise as articulately

as adults (Hill 2005, p64). The following section considers children's language development, associated theories and then considers this issue in relation to children's participation in research.

At around 1 year of age infants speak their first words. By 3 years of age, speech is largely understandable to adults and the child's vocabulary is around 1,000 words (Smith et al. 2003, p357). By the time a child enters school they have a vocabulary of some 14,000 words, their language use is correct and their basic sentence types are similar to those of adults (Smith et al. 2003, p357).

Language development that occurs during the first 5 years corresponds with the development of the sense of self and other (Symons 2004, p175). The incorporation of language into the infants' development of self concept is seen by using verbal labels – the words 'I', 'mine' and 'me' to describe themselves (Roth-Hanania et al. 2000, p4). The awareness of another's perspective is indicated by using words such as 'this' or 'that' and 'you.' These advances indicate the linguistic symbolic representation of the self and other (Lewis and Brooks-Gunn 1979, p6). The ability to combine the child's own perspective with those of others, and with outside events into a coherent account emerges over time and as a result of engaging in conversations with others (peers and adults).

The importance of the social and cultural origins of thought and the role of language in the structuring of thought was emphasised by Vygotsky (1997). In contrast to Piaget, who found that learning occurred from the inside out, Vygotsky theorised that learning occurred from the outside in – through the use of language by older members of the community (Greig and Taylor 1999, p30). According to Vygotsky, language is the cultural tool that allows the child to internalise thought and thought is born through words (Ratner 1991, p36). Ratner (1991) states that if any one idea is central to Vygotsky's writings, 'it is that socially provided language constitutes thinking, and consciousness in general' (p36).

Vygotsky (1997) described three stages of speech development. In the first stage, called social (or external) speech, speech is used to control the behaviour of others. Speech is used to express simple thoughts and emotions such as crying, laughter and shouting. An example of this form of speech is 'I want a drink.' The second stage -

private speech, or ‘speech for self’ is typical of the pre-school years (Bukatko and Daehler 2004, p265). Children talk out loud in an attempt to guide their own activities and may speak about what they are doing as they do it. An example is a child in school who counts out loud one block at a time saying each number as he/she goes along to get five. The final stage is inner speech. It is the interiorised form of private speech and the type of speech used by older children and adults (Bukatko and Daehler 2004, p265). According to Vygotsky (1997), once this final stage is reached, the individual is able to engage in all forms of mental functions.

This view of child development fits with symbolic interactionists’ understandings of meaning making, for in symbolic interactionism, meaning arises out of the social interactions people have with one another. Social life is expressed through symbols or gestures and language is considered to be the most important symbolic system (Annells 1996, p381). Meanings are produced and transmitted through language (Gusfield 2003, p123) and language shapes thinking, so that thinking is considered an inner conversation using language (Mead 1934). Understandings of the language skills of children participating in this study were another key aspect for the research.

Another area for consideration in this part of the discussion is the ethical approaches used in research with children. Children’s cognitive abilities, competence and language skills have significant influence on ethical aspects of such research. For instance, obtaining informed consent from primary school age children is not possible, but it is essential that young children whenever able give their assent. Ethical issues in research with children forms the focus of the next section.

Ethical issues in research with children

Ethical codes relating to children’s direct involvement in research are designed to assert and protect the interests and rights of children. Yet at the same time, research with children raises sensitive ethical considerations. When children are participants in research, ethical considerations that require specific attention and added vigilance are those of consent and assent, confidentiality and power differentials (Balen et al. 2006, p32). The study of ethics in research involving children has only in recent years been discussed in the literature. This lack may be attributable to children’s position in research that also reflects their place in society in general (Hill 2005, p61, Greig et al. 2007, p169).

Consent and assent

The issue of child consent in research is somewhat problematic. For example, there are differences in age recommendations for consent and assent and the term ‘child (or children’s) consent’ is often used interchangeably with ‘assent’ in the literature.

Consent implies complete understanding, and can only be obtained from those who have achieved full legal autonomy (Green et al. 2003, p701). In Australia, complete legal autonomy to consent to participate in research is not achieved until the age of 18 years (Green et al. 2003, p701). However, informed consent is not just a legality. There is also an ethical and moral responsibility based upon recognition of individual autonomy, free choice, dignity, and the capacity for self-determination (Kuther 2003, p344). Consent to participation in research should only be given after clear and understandable explanation of the purpose of the study, procedures and risks as well as benefits of participation have been reviewed (National Association of Pediatric Nurse Practitioners 2004, p21).

Assent is the term used in the context of consent from minor children who are not old enough to enter into a legal contract. Assent is defined as ‘a child’s informed agreement to the conditions of participation’ (Conrad and Horner, cited in Meaux and Bell 2001, p243). The elements of assent are information, comprehension and voluntariness, and voluntary agreement can be given by children and young people well before the age of legal consent. Assent is not a legally mandated process and is a term that has developed from the ethical and moral perspective. The assent process takes seriously the rights of children and their involvement in decision making (Broome and Stieglitz 1992, p148, Balen et al. 2006, p34).

In general, the guidelines for obtaining consent and assent are the same (Foreman 1999, p492). One difference is the amount of detail included in assent forms will vary according to the level of competence of the child. Further, assent should not be equated with consent, as indicated by Diekema (2003):

The purpose of assent is not to treat children as if they are capable of making decisions that are fully informed and autonomous as those made by adults... The assent requirement reflects the belief that even though some children might not completely understand or consider all the implications of research participation, their level of understanding and decision making ability are sufficient to decide whether they’d like to participate (p25).

The study of children's admission to hospital for surgery is a form of non-beneficial research and such studies can include for example, answering questions or providing a blood specimen. Reasons for obtaining assent from even very young children in the setting of non-beneficial research are outlined by Diekema (2003), and include the following: Firstly, obtaining assent is a reminder that children should be treated with dignity and respect. 'It would be disrespectful to attempt to involve children without first discussing the procedure and requesting their permission' (p25). Secondly, providing children a shared role in decision making benefits their development as autonomous individuals and their practice of self-governance. Thirdly, parents and researchers are reminded that children are individuals with interests. By failing to approach children to obtain their assent, the moral status of the children is diminished. Including children in a meaningful way 'recognises their status as partners in the research enterprise, empowers them to make a choice, ...and encourages a more respectful relationship between the child and investigator' (p26). Finally, a requirement for assent provides school age children with an opportunity to learn about respect for others. In seeking assent, adults model moral behaviour about respecting choices.

Competence and age of assent

Understandings of children's cognitive and moral development influences understandings about children's abilities to give assent (Alderson 1993, p62). Age is often used as a measure of a child's competence. For example, the Piagetian perspective of staged development is that children do not comprehend certain concepts before age 7. Piaget theorised that children under 7 years could not appreciate another's point of view so did not have 'role taking skills' (Alderson 1993, p62).

This traditional or intergenerational view of children compared to adults is described by Mayall (1994):

[t]he crucial distinction that makes children children is that they are not adults... they lack adulthood. This lack can be defined variously as deficiency, disadvantage, and/or oppression... What is common to the intergenerational relationship of children and adults is that children are inferior to adults. This inferiority is demonstrated in many ways: children are

not allowed to make decisions affecting them; must defer to adult knowledge and authority; have little economic power (cited in Jenks 2000, p70).

The recommended age when assent should be obtained from children varies. Some references state the age of assent as 12 years (Foreman 1999, p492); some guidelines state 7 years as the age assent should be initiated (Ondrusek et al. 1998, p164, Broome and Stieglitz 1992, p149); and studies have shown that children as young as 5 years are capable of giving voluntary assent (Meaux and Bell 2001, p246). Others recommend that there is no exact age where children are deemed to have the intellectual maturity to provide assent and the age remains at the discretion of researchers and ethics committees (Tait and Voepel-Lewis 2003, p609, Green et al. 2003, p701). This is because in addition to the age and competence of children, there are other factors that affect a child's ability to give assent. These include the child's psychological state, role constraints, family factors and consent-seeker factors (Meaux and Bell 2001, p244-248). The NHMRC (2007) advises that it is not possible to identify fixed ages as they vary from child to child. In addition, at the one time a child may be at different levels for different research projects, depending on the nature and complexity of the research (p55).

The child's experience can therefore be viewed as a more reliable indicator of maturity and competence. Further, children's competence can be viewed as being different from adults' not lesser (Kellett et al. 2004). An example of how misplaced adult preconceptions can be in relation to children's age and competence was provided in a research project about children's consent to surgery by Alderson (1993). When the researcher asked a ten-year-old girl 'So you are having the tops of your legs made longer?' the girl replied, 'I suffer from achondroplasia and I am having my femurs lengthened'(p7). According to Alderson (1999):

[c]ompetence can ... be seen as a variable construct rather than a fact, and is heavily influenced by the types of information, support and respect which the adults give to the child (p38).

Therefore, when conducting qualitative research with children, consideration should be given to each individual child's level of competence and understanding. Alderson (1999) calls for the researcher to look for 'emerging competence in every child' and

to work out with each child how much information and shared decision making seems to be in the child's best interests (p42-43).

Developmentally appropriate information

The development of assent documents for use with children requires more thought than when generating consent documents for adult participants. Recommendations for these materials prepared for the general population include firstly, use of written language at the reading level of 12 years of age, and secondly, that plain language, known as the 'standard register of language,' is used (Green et al. 2003, p701).

Examples for the title of a clinical drug trial for children using three different forms of language (formal, standard and informal) are provided by Green, Duncan, et al (2003, p701):

1. Formal: A multicentre, randomised, double-blind, cross over trial of the efficacy of Drug X in treating children with pulmonary disease
2. Standard: Evaluating the effect of Drug X on the immune system of children with lung disease
3. Informal: Testing a new drug for lung disease

The above authors recommend the title from the standard register is used in the consent documents for research because it allows reading without too much effort and relays the broad intent of the study. They suggest the informal title is too casual and carries the risk of sacrificing important aspects of information. The language in the standard register is appropriate for adults, for instance, the parents of prospective child participants. However, the needs of young primary school age children are best met by the use of the third title that uses informal language.

In reference to education for young children, Bruner (1960) calls for the teacher to be 'courteous enough to translate material into [a child's] logical form' (p243). Bruner (1960) also emphasises the importance of 'starting where children are' in terms of the information, the language and the images researchers offer to children (p243). This was an important concept that guided this research, and one area where this was evidenced was in the assent process used with children who participated in the research. The assent process is discussed in more detail in the next chapter.

The use of language when questioning children in the research process

As well as consideration in ethical aspects of research, language also plays a significant role in the questioning of children participating in research. Questions that might be asked of children in research that relate to their verbal skills have been described by Greig (2007, pp91-92) and include questions relating to the following:

- *Who? What and Where?* Even very young children are able to identify people, objects and places and can distinguish self from others.
- *Why? When? How?* Children of school age can consistently respond to questions that require explanation.
- *The past, present and future:* At around 4 years, children use past and future tenses and their notion of time improves when they commence school and they are able to deal with clocks and calendars.
- *Questions relying on memory:* Toward the end of primary school children have memory comparable to adults, and so some support may be required to assist the primary school aged child in remembering in order for the researcher to clarify who or what the child is referring to.
- *Sensitive questions:* Even quite young children do not supply a false picture and can tell the difference between truth and lies and that telling lies is wrong.
- *Reporting on knowledge and belief:* Preschool and early primary school age children can tend to agree with the questioner when open questions or statements are used. Young children can be literal and distractible and capable of invention.

Questioning of children therefore requires careful preparation. Questioning requires the use of clear instructions; drawing on appropriate supports (such as scaffolding for example, where caregivers provide support of children's conversations through offering words or concepts to the child, but do not direct the topic). Consideration of the context; attention to impression management; and the avoidance of leading questions are further issues for consideration (Greig et al. 2007, p92).

It is clear that language, of both researcher and of children, has an important place in research that directly involves children. This section has highlighted that in order to empower children and young people as research participants, information must be

provided to them at a comprehension level and in a medium that is appropriate for their age and development (Green et al. 2003, p701). The use of language is an important aspect of research that is child centred.

The next section of this chapter considers the development of a sense of self and the links that a sense of self has with symbolic interactionism is a part of the discussion.

Developing a sense of self

In child development theory, socially constructing a sense of self and other is recognised as a fundamental process in the child's development. When considering the development of a child's self concept and the role of self in social cognition, writers (including Chafel 2003, Lewis and Brooks-Gunn 1979, Light 1993) draw upon constructivist, symbolic interactionist and social-self theories of Charles Cooley (1902), George Herbert Mead (1934), Piaget, Vygotsky and others. In addition, strong parallels between the work of Mead and Vygotsky are made in the literature (Light 1993, Forrester 1992). Parallels in the work of Vygotsky and Mead include: the significance of understanding of self and other; the ability to take the others' perspectives towards oneself; that language is crucial in development of a self; and development is a fundamentally social process through which individuality is constructed (Light 1993, p191).

There are three important concepts that inform this discussion. Firstly, the development of a sense of self is the result of understandings that develop gradually and over a period of time in an ongoing process, described as a process-in-action (Chafel 2003, p214). Secondly, children are actively involved in constructing their own reality or view of the world. And thirdly, the development of a sense of self begins in infancy and continues throughout the lifespan (Roth-Hanania et al. 2000, p1).

According to symbolic interactionism, the self is a construct that arises out of interaction with the world (Blumer 1969, p12). Similarly, the concept of self and the knowledge of others in the development of social cognition can be considered as having three major aspects:

(1) knowledge of self, (2) knowledge of others and (3) knowledge of one's relationship to others... the child's knowledge of self and others is developed

through one's interaction with these others, and that social interaction is the basic unit out of which social cognition derives (Lewis and Brooks-Gunn 1979, p7).

Babies begin to develop a sense of self as they 'discover' and begin to explore their own bodies. Towards the end of the first year, infants acquire the knowledge of person and object permanence. In the instance of person permanence, the infant recognises another and searches for them when that person is no longer in view. In later infancy, children can recognise their own mirrored reflection, indicating further development of self-concept (Santrock and Yussen 1987, p468). Young children around the age of two years demonstrate a sense of self through independence and assertiveness, and through the imitation of other's behaviours in role play. In role play young children represent and practice their developing understanding of the social world (Bretherton 1984, pxi).

Mead (1934) argued the concept of self is learned through social interaction during childhood in play and games (p149). Mead described the role play that occurs in social pretend play as a major stage, called the 'play stage' in the development of a sense of self (Blumer 1969, p13). In imaginative play (role play) -

a child plays at being a mother, at being a teacher, at being a policeman; that is it is taking different roles... In the play period the child utilises his own responses to these stimuli which he makes use of in building a self (Mead 1934, p150).

The ability of children to understand how they are viewed by others is also important to the development of a sense of self. Mead's (1934) work supported the notion of 'the looking glass self,' initially described by Cooley (Cooley 1902), where the self is reflected through others: other people become the 'looking glass' for oneself (Lewis and Brooks-Gunn 1979, p12, Mead 1934, p151). By placing oneself imaginatively in the shoes of another the individual learns the human capacity of seeing self. Taking the role of the other is seeing the world from another's perspective and is important in understanding one's own behaviour in a situation. It is possible to anticipate and make sense of one's own conduct because a place to stand and a perspective from which to view self has been provided (Chenitz and Swanson 1986, p5).

Mead (1934) described how children further develop a sense of self in organised games:

the child who plays in a game must be ready to take the attitude of everyone else involved in that game ... he must know what everyone else is going to do in order to carry out his own play...
The game represents the passage in the life of the child from taking the role of others in play to the organised part that is essential to self-consciousness in the full sense of the term (p151).

Very young children do not have the ability to understand another's perspective of them. The capacity for perspective-taking increases with age once the child realises that others may have thoughts and emotions that differ from their own (Symons 2004, p162). At 2 to 4 years there is a large increase in children's skills in social interaction with peers and their abilities to take the perspective of another in simple ways. The ability to attribute mental states, such as beliefs, to another is called the theory of mind. This ability allows the child to interpret the behaviours of others in everyday social interactions (Andrews et al. 2003, p1476). Before the age of 4 or 5 years, most children experience difficulty with some aspects of theory of mind, such as the ability to recognize that others may hold beliefs that are not true, called 'false belief', or that others might have different attitudes to the same object and that they may take in different views on the same situation (Smith et al. 2003, p475). Children gradually come to understand that their actions will trigger reactions in others, and they begin to monitor their actions by acting differently, depending on which aspect of their social self they want to be seen (Santrock and Yussen 1987, p470).

Children's social play: Researchers have documented developing social behaviour in children's play activities, describing their engagement in 'solitary', 'parallel' and 'group' (including associative and cooperative) play (Smith et al. 2003, p141). In solitary play activity, the child plays alone and independently of others. In parallel activity, children play near each other but do not interact, for example playing side by side in a sandpit. In associative activity children interact doing similar things, for example adding blocks to the same tower. And in cooperative play, children interact in complementary ways, for example one child gets the blocks and then passes them to another who builds the tower (Smith et al. 2003, p141). Younger children of 3 years engage in solitary and parallel play more than older children and 5 year old children engage more frequently in group activities (Santrock and Yussen 1987,

p420). Group activities increase in size and frequency into the early school years. By the age of 6 or 7 children are entering into team games (Smith et al. 2003, p142). According to Mead (1934), children's participation in team, or organised games is required for the development of self-consciousness in the full sense of the term.

Research methods and their suitability for use with children

Choice of research methods is dependent on their appropriateness for the purpose and nature of the study. Both quantitative and qualitative approaches are suitable for use when children are directly involved (Greig et al. 2007, p59). Quantitative methods for research with children include observation, structured interviews and questionnaires. Quantitative techniques can vary according to children's ages; their conceptual abilities; their relationship with the researcher and the purpose of the research. Observational research techniques, for example, are particularly helpful for research that involves very young children who may not be able to communicate in other ways (Greig et al. 2007, p119).

Qualitative approaches present opportunities to capture children's experiences and understandings through rich description, that can incorporate actual words of children and also because such research is participatory in nature. Having said this however, qualitative research with children has its own difficulties and limitations. Real world research takes place in complex, messy and poorly controlled settings, and real world research with children is often even messier (Greig et al. 2007, p140).

Flexible, participatory, child centred research tools can be used with children and young people. These include photographs taken by children of places and things important to them; guided tours documented through tape, drawings and maps; mapping; individual interviews; focus groups and observation. Such methods may not be truly emancipatory, however, for numerous reasons. Children might not enjoy drawing for example; there may be a mismatch in tasks and children's literacy skills; participants may feel burdened by the level of participation asked of them; and there is a risk of over or misinterpretation of children's meanings (Greig et al. 2007, p159, 164). The way that methods are used, and the concepts and intent that underpin their use will influence their success and the research findings.

Childhood middle years – from 5 to 12 years is little researched and an oversight of the usefulness of qualitative methods applies for research with children in this age group (Greig et al. 2007, p161). One explanation for this is that by researching those who have few words (infants) and those who have many (adolescents) the problem of linguistic competence perceived to be associated with middle childhood is reduced (James et al. 1998, p177). In terms of child development, research has largely focused on the pre-school years and adolescence as these age groups have been viewed as being critical phases of development (Greig et al. 2007, p162). Because there has been little research with children aged between 5 years and 12 years, there is a gap in understanding. This current research is with primary school children aged between 6 and 12 years and so this study helps to address this lack and adds to the body of research with children of this age.

Grounded theory as a research approach with children

Grounded theory is especially useful in situations where little is known about a topic or where a new outlook is needed. It is therefore a method suitable for research into the world of children, where researchers can utilise innovative ways of conducting the research (Greig et al. 2007, p141). Whilst grounded theory is a recommended approach for exploring children's perceptions of their experiences (Woodgate 2000, p194), there is only a limited, albeit growing, number of studies where a grounded theory method has been used in conducting research with children. One reason for the limited number of studies may be that in general, we do not have a well established research tradition with children as participants. Of the limited grounded studies with children, there are nurse researchers who have used the approach with hospitalised children. These grounded theory studies enable the experiences of children to be explored in their richness with a result that understandings of the phenomenon of children's healthcare, their hospitalisation and illness are improved.

Hospitalised children's perceptions of their pain experiences were explored in a grounded theory study conducted by Woodgate and Kristjanson (2000). The very young children in the study were aged between 2 1/2 years and 6 1/2 years, and data collection techniques used by the researchers included participant observation, interviews, play and drawings. The authors found that through the use of qualitative research methodologies, it was possible to enter the world of young children and

learn of the meanings children assign to their experiences, in this instance, their experiences of pain.

A grounded theory approach was used to explore children's, parents' and health professionals' experience of childhood chronic illness in research by Sartain, Clarke and Heyman (2000). Child participants in this study were aged between 8 and 14 years and data collection techniques used with the children included interview and drawing. This study found that children are capable of giving an opinion and that their views can lead to significantly greater understandings of biography in childhood chronic illness.

Stewart (2003) conducted a grounded theory study with 11 children aged between 9 and 12 years who were undergoing treatment for cancer. The two themes consistently identified in the analysis were the 'uncertainties' inherent in the children's illness experience and the process the children described was that of 'getting used to it' (p398).

A grounded theory study involved children's, parents' and nurses' views on participation in care in the healthcare setting was conducted by Coyne (2006). The findings of the study revealed that parents and children experienced considerable disruption to their worlds and experienced difficulties in their participation in care (p65). The core concept of Coyne's study was 'finding a balance' that described a process 'used by children, parents and nurses to achieve equilibrium between their social worlds and the social order of the ward' (p65). Coyne's grounded theory incorporated the child, the parent and the nurse.

Wennstrom et al's (2008) grounded theory study involved 20 children aged 6 to 9 years who attended hospital for day surgery. Data collection techniques included observation, interviews and drawings. This interventional study used perioperative dialogue that involved extensive pre-operative preparation, recognition and support throughout the entire perioperative experience. The core category identified in the research was 'enduring inflicted hospital distress'.

These studies are from the discipline of nursing. In sociology, Greig and Taylor (1999) refer to the appropriateness of a grounded theory approach for research with children:

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. Hence, the qualitative framework entails a methodology in which theory is 'grounded' in data such as observations, interviews, conversations, written reports, texts and their interpretations (p43).

Grounded theory is a recognised approach for learning more about an area of study, and what research participants' lives are like. Grounded theory is an appropriate method to use when research involves children and the aim is to learn about children's lives (Greig et al. 2007, p141).

Conclusion

Whilst children are increasingly acknowledged as social actors in their own right, traditionally, there has been little attention given to children as active participants in research. However, children are the primary source of knowledge about their own experiences. This work adds to the small but growing body of nursing research with children where children's experiences of healthcare are explored from children's own perspectives.

Children's participation in research involves changes in emphasis and approaches so that children are recognised as subjects rather than objects of research. Children's special needs in the research process need to be acknowledged so that they are not adversely affected by their participation. Understanding of children's development, their language skills and the ways children develop understandings through experience is important in research that directly involves children as participants. In this study, child development theory informed the research process and methods, the way information was provided to children and the ways children were questioned in interviews. Child centred research approaches acknowledge these issues and provide strategies to address them. Attending to the specific ethical considerations for research with children helps to protect children from exploitation. Obtaining children's voluntary and informed assent to participate is one way of protecting children from harm and also demonstrates respect for children.

Research methods suitable for research with children aged 6 to 12 years were essential to this research. A constructivist grounded theory approach that

incorporated child centred research techniques was chosen to achieve the research aim. Grounded theory has been shown to be a suitable method for use with children and child centred techniques facilitate children's participation; acknowledge the competence and abilities of different children; and address specific ethical aspects of research with children. The aim of this current research was to explore children's experience of admission for surgery, through listening to them and hearing what they have to say. In doing so, this is an example of research *with* children, rather than *on* them.

Chapter 4: The research strategy and design

Let's go to the palace said one blind man... a friend of the six blind men met them at the palace and an elephant was standing in the courtyard. The six blind men touched the elephant with their hands... 'An elephant is like a wall' said the first blind man. 'A wall?' said the second blind man. 'You're wrong, an elephant is like a snake.' The third blind man said 'You're wrong, an elephant is like a spear.' The fourth blind man said 'No, you're wrong, an elephant is like a tree' ...

The Rajah looked out and saw the blind men arguing in the courtyard. 'Stop' said the Rajah. 'The elephant is a big animal. Each man touched only one part. You must put all the parts together to find out what an elephant is like' (From The Blind Men and the Elephant retold by Lilian Quigley 1959).

The purpose of this chapter is to give an account of the research design, strategies and methods used in this study, and so provide judges of the work a guide that assists in their assessment of its integrity. In this qualitative study a constructivist interpretive perspective provided the general orientation for the work. This approach was chosen because it suited the research aim and because it reflects my own perception of the world. Grounded theory conducted from a constructivist perspective (Charmaz 2000, 2005, 2006) was the methodological approach used to explore the experiences of primary school age children admitted to hospital for surgery. This research design therefore involved the 'intersection of philosophy, strategies of action and specific methods' (Creswell 2009, p5). The design reflects the research aims, questions, and epistemological understandings appropriate to this study.

A qualitative research approach

My own beliefs and feelings about the world and how it should be understood and studied influenced the choice of research paradigm and determined the research strategies and methods for this study (Denzin and Lincoln 2005, p22). An account of my biography was provided in the introductory chapter of the thesis, and provides a sense of my worldview, or ontological perspective. This study recognises that the dominant positioning of traditional ways of knowing have rendered other ways of knowing, such as through interpreting meaning, as unexplored and underdeveloped. It also recognises that an emphasis on objectivity; generality; and one unitary truth serves to reduce the rich complexities of human experiences (Charmaz 2006, p5).

Qualitative researchers ‘study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them’ (Denzin and Lincoln 2005, p3). The use of a qualitative approach in this study allowed me to explore the meanings the children ascribed to their admission to hospital for surgery, from their perspective. As well as the importance of meaning, the approach addressed the importance of context and process, within the children’s experience of hospitalisation and surgery. These three aspects would not have been components of the research if a quantitative approach had been used. Strengths of qualitative research approaches include their ability to provide complex textual descriptions of how individuals experience a given research issue, with the potential for rich understandings of the studied phenomenon.

Four major interpretive paradigms structure qualitative research: positivist and postpositivist; constructivist-interpretive; critical and feminist post-structural (Denzin and Lincoln 2005, p22). Of these, the constructivist-interpretive paradigm was chosen for this study, in acknowledgement of the subjective nature of the research and the multiple realities of those involved in the study.

A constructivist-interpretive paradigm

A paradigm or worldview is defined as a basic set of beliefs that guides action (Denzin and Lincoln 2005, p22, Creswell 2009, p6). The research paradigm for this study incorporated my ontological perspective (my own worldview); my epistemological perspective (how my ontological perspective on existence/reality related to the theories and analysis used); and methodological perspectives (the assumptions that guided my choice of research methodologies) (Love 2002, p410). Because of my own philosophical assumptions and values, and the nature of the research project, constructivism and interpretivism were chosen as the qualitative research paradigms for this study. Interpretivism and constructivism are often combined (Creswell 2009, p8) and as such, constructivist-interpretivism guided the research. A constructivist research paradigm assumes a relativist ontology (there are many realities) and a subjectivist epistemology (participant and researcher co-create understandings) (Denzin and Lincoln 2005, p24).

The major elements and assumptions of a constructivist-interpretive worldview that were incorporated into this research include:

- That individuals seek understanding of their world and that they develop meanings of their experiences through interaction with others;
- That participant meanings are multiple and layered; and
- That reality is co-created by the participants and the researcher and that the researcher is a part of the world they study and the data they collect.

My worldviews shaped the approach to the study in the following ways. They influenced the choice of research topic; the choice of research paradigm to guide the study; the choice of theoretical framework and major data gathering and data-analysis methods; the choice of context; the ways values already present within the context were managed; and the ways findings were presented (Guba and Lincoln 2005, p197).

However, perspectives from other paradigms were also incorporated or blended into this study. Symbolic interactionism as a theoretic frame has informed this work, and is discussed on page 76. The work also reflects a political and ethical commitment on my part to giving children a voice and to incorporating participatory processes that included children in this study (Guba and Lincoln 2005, p201). There is criticism that a constructivist-interpretive stance does not go far enough in advocating for an action agenda to help marginalised groups (such as children who are hospitalised and who lack a political voice) (Creswell 2009, p9). The very idea of co-constructing knowledge, however, implies that there is an openness to the possibility of a change response to what it is that children say (Graham and Fitzgerald 2010, p7).

Constructivist grounded theory as the strategy of inquiry

Constructivist grounded theory, incorporating child-centred research techniques, was found to be the most appropriate strategy of inquiry for this study. It presented a method that enabled the phenomenon of study, which was primary school age children's admission to hospital for surgery, to be explored and for the processes the child participants were engaged in to be revealed. The studied experience is also referred to as the phenomenon in constructivist grounded theory (Charmaz 2004, p986). Constructivist grounded theory as the strategy of inquiry provided specific

direction for procedures in the research design (Creswell 2009, p11). These processes are discussed later in this chapter under research methods, and taken up in the following chapter detailing data collection and analysis.

In this study, as is consistent with constructivist grounded theory, it was assumed that reality was co-created by the participant children and myself as researcher; that I was a part of the world I studied and the data I collected. Constructivist grounded theory differs from traditional or classical grounded theory that considers the participant's reality is discovered by the researcher, and that theory emerges from the data quite separate from the researcher. Constructivist grounded theories are constructed through the researcher's 'past and present involvements and interactions with people, perspectives, and research practices' (Charmaz 2006, p10) and what the researcher brings to the data influences what they see within it (Charmaz 2006, p15).

Constructivist grounded theory retains the rigour of the traditional grounded theory method, whilst it fosters openness and reflexivity and encourages empathetic understanding of the participants meanings, action and worlds. According to Charmaz (2006, p185), this approach adopts the tools of grounded theory but does not support the objectivist and positivist assumptions of the more traditional method. The result is that theoretical analyses in constructivist grounded theory are interpretive renderings of a reality rather than objective reportings of it.

An overview of constructivist grounded theory

Researchers need to be familiar with GTM [grounded theory method], in all its major forms, in order to be able to understand how they might adapt it in use or revise it into new forms and variations (Bryant and Charmaz 2007b, p17).

My approach explicitly assumes that any theoretical rendering offers an interpretive portrayal of the studied world not an exact picture of it (Charmaz 2006, p10).

Grounded theory served as a way to learn about the world of study, that is the experiences of primary school aged children admitted to hospital for surgery, and a method for developing a substantive theory to further understandings of that world (Charmaz 2006, p10).

The grounded theory method is an approach for conducting inquiry for the purpose of constructing theory (Bryant and Charmaz 2007b, p1). The roots of grounded theory are in Chicago sociology, symbolic interactionism and pragmatist philosophy (Charmaz 2006, p7). Sociologists Barney Glaser and Anselm Strauss originally developed the grounded theory method, described in the foundational work *The Discovery of Grounded Theory* (1967). According to Glaser and Strauss (1967), the aim of grounded theory is to generate theory and grounded theory can be defined as ‘the discovery of theory from data systematically obtained from social research’ (p2). The work was presented as ‘a beginning venture in the development of improved methods for discovering grounded theory’ not as ‘clear-cut’ procedures and definitions’ (Glaser and Strauss 1967, p1). The methodological approaches to grounded theory have evolved and changed with the socio-political and intellectual context (Dey 2003, p80) and the different methodological approaches have resulted in different interpretations of grounded theory. The classic or traditional perspective is described in the works of Glaser and Strauss (1967); Glaser (1978); and Strauss and Corbin (1990). The key works that present a postmodern or constructivist perspective include the work of Charmaz (2000, 2005, 2006) and Clarke (2005).

This study utilised the grounded theory processes of coding data, then grouping these codes into concepts so that ultimately, theoretical models emerged. Authors such as Charmaz and Clarke contend that the basic grounded theory guidelines, such as coding, memo-writing, and sampling, can be combined with ‘twenty-first century methodological assumptions and approaches’ (Charmaz 2006, p9). Charmaz’s version, therefore considers the classic statements of grounded theory but ‘re-examines them through a methodological lens of the present century’ (Charmaz 2006, pxii).

Grounded theory is an inductive research approach and the substantive theory that was developed in this study was ‘grounded’ in data from the field because the goal was ‘to generate a theory that accounts for a pattern of behaviour which is relevant and problematic for those involved’ (Glaser 1978, p93). This work focused particularly on the actions, interactions and social processes of the children participating in the research around the time of surgery. In so doing, it has revealed how the children made sense of their situation. Grounded theory has been described

as the preferred research method when wanting to learn ‘how people manage their lives in the context of existing or potential health challenges’ (Schreiber and Stern 2001, pxvii).

As well as being an inductive method, grounded theory is also explicitly emergent. So in this research, rather than beginning from a position of an existing theory and predefined concepts, the theory was discovered from the data. In keeping with the method, initial decisions for the theoretical collection of data were based on a general perspective rather than a preconceived theoretical framework (Glaser and Strauss 1967, p65).

Consistent with grounded theory, data analysis and data collection occurred simultaneously, each informing and focusing the other, and the specific focus of the research emerged as the analysis proceeded (Glaser and Strauss 1967, Charmaz 2005, p508). Grounded theory required that increasingly abstract ideas were developed about the children’s meanings, actions and words (Charmaz 2005, p508). It also required that attention was given to concepts and processes that were conceptually determined from my own interpretations of the data. Charmaz (2006) emphasises the analytic aspects of grounded theory inquiry, at the same time recognising the importance of a solid foundation in data. Rather than describing the material/data, grounded theory required that I move to ‘conceptualising it in analytical frameworks’ (Charmaz 2006, pxii).

This study recognised that it was not possible to completely share children’s perceptions and understandings. In this constructivist grounded theory, data and analysis were created from my shared experiences and relationships with participants and other data sources (Charmaz 2006, p130). The study examined how, and why, the participant children constructed meanings and actions in relation to the phenomenon that was their admission to hospital for surgery. This was achieved by my moving as close to ‘the inside of experience as possible’, at the same time realising however, that it was not possible for me to replicate the experiences of the participants (Charmaz 2006, p130). This approach required: a sense of reciprocity between myself as researcher and the children in the co-construction of meaning; the recognition of potential power differentials and ways of modifying these; and clarification of my own (as researcher’s) position (Mills et al. 2006a, p10).

Constructivist interviewing recognised the co-construction of meanings created through the discourses of the children and myself.

Strengths and limitations of grounded theory

All research methods have their own strengths and weaknesses. Various critiques of grounded theory as a method include claims of epistemological naiveté; a ‘slipshod’ attention to data collection; that the inductive nature of the method is ‘ad hoc’.

Further, that a reliance on secondary sources exposes the method to potential bias; a questionable justification for small samples; and an incompatibility with macro questions (Bryant and Charmaz 2007a, p36). Charmaz (1995) argues that a constructivist approach to the ‘interactive nature of both data collection and analysis resolves the criticisms of the methods and reconciles positivist assumptions and postmodernist critiques’ (p62).

A critique of constructivist grounded theory as described by Charmaz has been offered by Glaser. In an article outlining his critique, Glaser (2002) states that the co-construction of understandings between researcher and participant results in the ‘unwanted intrusion of the interviewer’ (paragraph 8). However, the postpositivist stance of a neutral observer (such as espoused by Glaser) is rejected by constructivists.

Mills et al (2007) claim that grounded theory provides great potential for nursing research because it seeks to discover issues of importance in participants’ lives. Yet in its traditional form, grounded theory does not value the reciprocal nature of nurses’ relationships with patients/participants. The reciprocal nature of nurses’ relationships with participants that nurses themselves see as important, however, is recognised by constructivist grounded theory. Further, constructivist grounded theory reformulates research relationships and places emphasis on making the researcher visible and their theory about the area of interest reflective of participants’ words (p78).

In refuting criticisms of grounded theory, such as those raised by Glaser, Charmaz (2006) names the following crucial points. Firstly, theorising is an activity and grounded theory methods provide constructive ways to proceed with this activity. Secondly, the research problem and the researcher’s unfolding interests can shape the

content of this activity, not the method; and lastly, the products of theorising reflect how researchers act on these points (p134-135).

Grounded theory as a research approach with child participants

Children's understandings of their hospitalisation for surgery is an area that needs further exploration from the perspective of children themselves. Grounded theory makes valuable contributions in areas where little research has been conducted (Chenitz and Swanson 1986, p7) . In addition, grounded theory is recognised as an appropriate approach when the intent of research is to understand the child's perspective of an experience (Woodgate 2000). In this study, the approach was used as a way of giving voice to the children's constructions of their situation; what was relevant, interesting and important to them. Grounded theory provided a way of exploring the perspectives of children themselves, the meaning of what was going on, and how these related to their expectations.

In grounded theory studies with children, as in all grounded theory studies, existing theory is not the driving force for conceptualising their lives - theory emerges from the data under investigation. For this study, an understanding of how the children dealt with their circumstances required foregrounding their agency as social actors, their experiences and understandings, their interactions with others and their strategies for action (James et al. 1998, p138). As a researcher I wanted this work to be connected directly to the children's experience of admission to hospital for surgery, where they are positioned in that phenomenon, and what they think about it. In considering the understandings of primary school age children who undergo surgery, I was concerned with finding out what was going on. I wanted to discover how children made sense of their experience; and the factors they identified that influenced, enhanced or impeded their experience.

Giving children a voice meant taking children seriously and putting their views at the centre of analysis (France et al. 2000, p151). This study required the implementation of a research approach that was child centred - that enabled children to be situated as the central focus and that recognised their interactions and cultures as worthy of study. A constructivist grounded theory approach meant that I immersed myself in the data in a way that embedded the children's narratives in the research outcomes. This was achieved initially through the use of coding language that was active in its

intent, through to the children's voices and intents being presented in the theoretical rendering.

It is a delicate balancing act, enabling participant's accounts to retain a degree of visibility in the text so that the reader can make the connections between analytical findings and the data from which they were derived. Making such connections clear however, demonstrates the value the research places on the participant as a contributor to the reconstruction of the final grounded theory model. It also meets the researcher's ethical obligation [to faithfully describe the experiences of others] (Mills et al. 2006b, p6).

The approach used in this study needed to conceptualise and recognise children as competent reporters of their own experiences. Constructivist grounded theory, underpinned by symbolic interactionism met this requirement. The next section provides an overview of symbolic interactionism and its congruence with this study is also identified.

Symbolic interactionism: a theoretical frame for the research

Symbolic interactionism was considered as a theoretical frame underpinning this grounded theory research. Both symbolic interactionism and grounded theory emphasise that people act as individuals and as a collective, and both focus on the studying of processes (Bryant and Charmaz 2007b, p21). A major strength of a grounded theory study is the interactionist perspective of understanding an issue or concern from the perspective of those affected by it (MacDonald 2001b, p121).

The aim of this study was to explore the experiences of children admitted to hospital for surgery from their perspective, and so increase understandings of what the experience is like for children. This study aim was to explore what the experience of hospitalisation and surgery was like for children and what the children found to be important about that experience. Symbolic interactionism provided an appropriate framework for the research aim. A symbolic interactionist perspective emphasises the importance of understanding what individuals know about their world and what they believe is important (Benzies and Allen 2001, p545). Further, questions from a symbolic interactionist perspective focus on how individuals interpret meanings and act in specific contexts. In this study, the meanings children made within the context of their admission and surgery were a focus of the research (Benzies and Allen 2001, p545).

Symbolic interactionism is viewed as a theoretical perspective (Charmaz and Lofland 2003, Milliken and Schreiber 2001, Crotty 1998) concerned with the relationship between individuals and society; the way human beings make meaning of events or reality and the way they act in relation to these beliefs (Chenitz and Swanson 1986, p4). In symbolic interactionism, human beings are viewed as active participants and creators of the world in which they live (MacDonald 2001a, p117). This is relevant to this study, where children are viewed as social actors in their own right and their language, their meanings and actions were attended to in order to explore the phenomenon of interest and to achieve the research aim.

Symbolic interactionism was developed from the philosophical theories of George Herbert Mead whose collected works *Mind, Self and Society* (1934) were published posthumously. Central to symbolic interactionism is the concept of self (Annells 1996, p381). In addition, the study of symbolic communication through gestures in social interactions is an important concern of symbolic interactionism. Mead (1934) conceived society as an exchange of symbols or gestures and a main symbol system used by humans is oral language (p146). Herbert Blumer (1969) is credited with the further development of the classical or Chicago School of symbolic interactionism that emphasises the interpretive process in the construction of meaning. (A second school, developed under Manford Kuhn and known as the Iowa School, was strongly influenced by positivism) (Benzies and Allen 2001, p543).

Three basic assumptions of symbolic interactionism described by Blumer (1969) are meaning, language and thought and these core principles lead to conclusions about the concept of self and interaction in society. According to Blumer:

1. 'human beings act toward things on the basis of the meanings that these things have for them;
2. the meaning of such things is derived from, and arises out of, the social interaction that one has with one's fellows; and
3. these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters' (p2).

In an interactionist approach, truth is not absolute because meanings change depending on the context and 'coming to know entails searching for ways to

understand the meaning of a situation from the perspective of the individual and societal groups' (Benzies and Allen 2001, p544).

A criticism of symbolic interactionism is that it is limited to micro-level aspects of social life and is unable to deal with wider macro-level social processes, such as institutions, power and social structure (Dennis and Martin 2005, p194). This study was concerned with the micro-level processes of children's admission and surgery, from their perspective and sought to explore how the children participating in the study defined; understood; interpreted; and therefore managed the situation they were in. However, it was also a study about children (a group who do not have a voice) who were admitted to hospital (healthcare is an institution that is not a normal part of children's lives, as schools are). The children were required to interact with a large number of people, both children and adults, including strangers. In wanting to present the phenomenon from the perspective of children, children have been given a voice and their experiences and perceptions have been revealed. This was achieved by children's direct involvement as active participants in the study.

In summary, the suitability of a grounded theory and symbolic interactionist approach to this research has been addressed in this section. Grounded theory informed, by symbolic interactionism, is concerned with understanding an issue or concern from the perspective of those affected by it. This study aimed to explore children's admission to hospital and surgery from their perspective. The call for children to be understood as social actors shaping as well as shaped by their circumstances is central to this study and is congruent with a grounded theory approach that is underpinned by symbolic interactionism.

The research methods

This section provides an outline of the research methods that were used to address the research aim to explore children's admission to hospital and surgery from their perspective. The research design was based on a constructivist grounded theory method and child-centred research techniques that were appropriate to use with children aged between 6 and 12 years. This research utilised approaches suitable for children and methods based on children's skills that resulted in the generation of rich and relevant data (Punch 2002, p330). The use of a constructivist grounded theory

approach following Charmaz (2000, 2005, 2006) guided the methods of data-gathering as well as theoretical development. As has been established, research with children as participants needs to start with the understandings that children bring, their language and the various ways they use to communicate their understanding (Wetton and McWhirter 1998, p269). Ethics and research with children was considered in Chapter 2 of this work. A commitment to meeting the required ethical standards for conducting research with children was a major concern of the study, and the next section outlines in detail how ethical considerations were specifically addressed in this study.

Ethical considerations for this research

The UNCRC recognises children's rights in relation to consent and assent in several articles in the Convention. Article 12 affirms children's right to express their opinions and have these taken into account in any matters that affect them, while Article 13 recognises children's right to freedom of expression and access to information about matters affecting them (UN 1989). Participation in any matters affecting children clearly includes participation in research. There is an obligation to ensure that children's rights in research ethics, including their right to participate, are respected and integrated into policies and documentation.

Ethical judgments in this research were made throughout the research: at the beginning of the process around conceptualisation and research design; during the course of the research in terms of data collection and analysis, and towards the end of the process in considering reporting methods (Edwards and Mauthner 2002, p19). An overly protective stance toward children can result in reducing children's participation in research. Equilibrium was therefore needed so that the children were able to participate in the research and when doing, so their rights and interests were fully protected. The goal was to include children in a way that protected them from possible harm and exploitation and at the same time allowed their participation in ways where their experiences and knowledge were revealed.

Key principles of an ethical approach to research include respect for persons, equity, non-discrimination, and beneficence and these general principles were incorporated into the framework for the research (Hill 2005, p66). Key ethical topics and associated questions developed by Alderson (1995) provides an inventory for

researchers conducting research with children as participants and is presented in Table 2 (p81). The way these research questions were specifically applied in this study are outlined in column three of the table.

In addition, important ethical considerations taken into account in conducting this research included the levels of children's competence, their vulnerability, power differences between myself as researcher and the children and issues around access (Garden 2007, p22). The way that these considerations were taken into account in this study included the following:

- Acknowledgement that children's competencies, perceptions and frameworks of reference were different at different ages, as well as in children of similar ages. This had implications for the consent process, methods of data collection and interpretations of the data.
- Children can be vulnerable to exploitation in interactions with adults, and therefore my responsibilities to the children participating in the research were an essential consideration.
- The differences in power between us could become problematic at the point of interpretation and presentation of findings, so that reflexivity was another essential part of the research process.
- Access to children was mediated through gatekeepers, including the children's parents and the healthcare providers, including at organisational level and through the nurses within the unit.

In Australia, the rights of children involved in research are addressed at the national level, for example by the NHMRC (2007) in the National Statement on Ethical Conduct in Research. This statement is applicable to all research involving children and young people. At a local level, the rights of children involved in research are addressed through bodies such as ethics committees.

Table 2: Key ethical considerations in research with children (based on Alderson, 1995, in Hill 2005, p66).

Topic	Sample Questions	Application in this Research
1. Research purpose	Is the research in the children's interests?	Increased understandings of children's experience of hospitalisation for surgery can positively influence care practices for children who are hospitalised.
2. Costs and benefits	What are the risks for children of doing or not doing the research? What are the potential benefits?	There was no direct benefits to the children participating in the study – although the opportunity to reflect on their experiences may have assisted them to make meaning of the experience.
3. Privacy and confidentiality	What choices do children have about being contacted, agreement to take part, withdrawing, and confidentiality?	An independent gatekeeper ascertained children's initial interest to participate in the research before they were approached by the researcher. Children provided written and verbal assent to participate and could withdraw their assent at any time. No information leading to identification of children is provided in the reporting of the research. Children chose whether parents would be in attendance during interviews and their confidentiality was respected. Decisions were made in consultation with the child, parent and nurse as to timing and place of interviews.
4. Inclusion and exclusion	Who is included, who is excluded? Why? What efforts are made to include disadvantaged groups (eg those with physical impairments, homeless young people)?	Children were English speaking. So as to avoid causing increased stress or distress, children experiencing a serious illness were not included in the study. Children with physical or cognitive impairment were not excluded from participating.
5. Funding	Are funds 'tainted'? Are resources sufficient? In what circumstances should children be compensated?	This research was not funded. Children were given a packet of colour felt pens to do drawings and stories and to keep. Compensation was not required in this study (eg there were no added travel costs to families participating).

6. Involvement and accountability	To what extent can children or carers contribute to the research aim and design? What safeguards and checks are in place?	Children participated in the development of the children's assent documents for this research. Children and parents were able to choose the extent of involvement in the study (for example one child wished to do a drawing and story and not be interviewed).
7. Information	Are the aims and implications clearly explained? Is written documentation available in other languages?	The readability of the assent documents were determined using validated tools, ensuring they were in a language appropriate for this group of children. Individual children's understandings of the research aim and what their participation would entail were confirmed prior to their participation.
8. Consent	How well are rights to refuse cooperation explained and respected? Are informal 'pressures' used? What is the correct balance of child and parental consent?	An independent gatekeeper identified children suitable for the study. Parent permission was obtained before approaching prospective children. Both parent consent and child assent was required for this study.
9. Dissemination	Do participants know about and comment on the findings? How wide is the audience for the research – academics, practitioners, policy makers, the public, research participants, etc?	The audience includes practitioners who are involved in the care of children who are hospitalised and academics. People involved in making policy decisions around the care of children in hospital is also an intended audience for this research.
10. Impact on children	How does the research affect children through its impact on thinking, policy and practice? Are children's own perspectives accurately portrayed?	This work has the potential to impact on the way children are cared for around the time of their admission for surgery. This is through increased understandings of children's experience from their perspective.

The study method and circumstances in which the study was conducted specifically met the criteria for research involving children and young people as described in the NHMRC Human Research Ethics Handbook Section 4: Research involving children and young people

(http://www.health.gov.au/nhmrc/hrecbook/01_commentary/04.htm). The following aspects of the research are areas consistent with the NHMRC criteria:

- The research project was deemed important to the care of children who undergo surgery.
- The participation of primary school age children (6 - 12 years) was indispensable because information available from research with other individuals would not provide the information required.
- The study method was appropriate for children.
- The circumstances in which the research was conducted provided for the physical, emotional and psychological safety of the child.

The ethical framework for the research involved a number of processes to ensure the work was consistent with the requirements for the conduct of ethical research with children. The processes included the following:

- Ethics approval for this study was obtained from the appropriate ethics body, the Human Research Ethics Committee (Tasmania) Network. This Network provided the approvals required for both the university and the hospital (ethics approval number H8117).
- Ethics approval included that permission was obtained from the heads of the relevant departments within the hospital, including Paediatrics, Paediatric Surgery and Perioperative Services.
- Relevant treating Consultants were informed of the research.
- Nurse Unit Managers of the relevant units were informed of the research and information sessions were conducted with groups of nursing staff (as well as other relevant staff) from these areas.
- Regular meetings were conducted with Clinical Nurses during the periods of data collection, seeking children who fit the inclusion criteria for the study and who might be suitable to approach about participating.

- The initial approach made to parents of potential participant children was made by the nurse caring for the child – who was therefore acting as ‘gatekeeper’.
- My own approach to these parents seeking their permission to approach their children.
- My approach to potential participant children seeking their assent.

In acting as independent ‘gatekeepers’, staff of the Paediatric Unit provided parents of prospective participant children with initial information about the study and obtained the parents’ agreement to my contacting them to discuss the research in more detail. The nurses who acted as gatekeepers were involved in caring for the children and so had a good understanding of the children’s condition and suitability for this initial contact.

In recognition of their role as advocates for their children, parents were approached for permission for me to speak with the child before I approached the child. In the initial approach to parent and child, a Parent Information Sheet and Child Information Sheet (called *The Information Letter*), were provided outlining the purpose of the study (Appendices 1 - 4 present sample consent and assent documents used in the study).

When they were given the assent documents, sometimes the children read the documents independently and at other times I read *The Information Letter* and *The Letter That Gives Your Permission* (the child assent document) out loud with the children. This was in recognition that not all of the children participating in the study would have the literacy skills required to read the documents independently. When reading the documents, the child’s understandings were checked to ensure that each child understood the intention of the research and what their participation would entail.

A child’s refusal to participate in the research was respected. In fact, there was only one child approached to participate who declined to do so. All other children asked to participate readily agreed. Parents and children received a copy of the signed consent and assent to keep. Voluntary, informed written consent was obtained from the

children's parents and voluntary informed written assent was obtained from each of the children participating in the study.

Developing assent documents for the study

In the process of developing the children's information sheet and assent documents for the study, inadequacies and inconsistencies in the guidelines and general literature were identified. Exemplars provided in the literature, and by ethics committees, were not consistent with the requirement that information be provided at a comprehension level and in a medium that is age appropriate, especially for children less than 12 years of age.

In developing the assent documents for this research, it was important to resolve the contradictions that existed in an espoused child-centred approach to research and the traditional consenting process that virtually excludes children's voices. First attempts to develop child information sheets and assent forms remained unsatisfactory. In response to this issue, a group of primary school children were invited to participate in developing the research information sheet and assent form for use with children in this study (Ford et al. 2007) (refer to Appendix 8). The children who took part in this activity were aged between 6 and 12 years and they worked in small groups with an adult (a teacher; teacher's aide or myself) to assist them to determine the information to be included in these documents. The children decided on the content and language of the documents that they named *The Information Letter* and *The Letter That Gives Your Permission*. The process resulted in a research information sheet and assent form for children, written by children that provided the information that children were most likely to need, in a form that they could readily understand.

The assent documents that were developed with the children for use in this current study were assessed for their readability using validated, reliable tools: the Flesch-Kincaid Grade Level Scale (up to Grade 12) and the Flesch Reading Ease Scale (a 100 point scale) – these tools are available through the Microsoft Word© software package. The assent documents prepared in collaboration with the school children for this study had a readability score of Grade 3.9 according to the Flesch-Kincaid Grade Level score and the Flesch Reading Ease was 86.3 (out of 100). Table 3 presents the readability statistics of the children's assent documents.

Table 3: Readability statistics (from the Microsoft Word© Program)

Counts	
Words	303
Characters	1270
Paragraphs	25
Sentences	25
Averages	
Sentences per Paragraph	1.3
Words per Sentence	11.2
Characters per Word	3.9
Readability	
Passive Sentences	0%
Flesch Reading Ease	86.3%
Flesch-Kincaid Grade Level	3.9

The language used in the child assent documents was quite different to that of first drafts and to examples found within the literature. For example, instead of saying ‘an adult has read this information sheet with me’ as was in an earlier draft, the children chose to say ‘I have read the information letter with Karen’. ‘The talk will be tape recorded’ became instead ‘Karen will record my voice on a tape when I talk to her’. These statements, like the entire documents, are in the active rather than passive voice. The active voice is recommended for increased clarity and ease of understanding. In addition, the children chose to use my given name rather than refer to an anonymous ‘adult’.

The development of the assent documents with children demonstrated the commitment to ensuring the research was presented to children in a language they were able to understand. This was one way for them to have control in their decision whether to participate in the research or not. The process of developing assent documents with children had not previously been described in the literature.

Addressing potential risks to participating children

It was recognised that admission to hospital and surgery are stressful experiences for a child and family and that discussing these experiences could cause potential further stress to them. Therefore, all participants were offered the opportunity to debrief with the Social Worker attached to the Paediatric Unit. If a child was to become distressed during the course of an interview, the interview would be terminated and the Social Worker would be asked to attend to provide a debriefing. In reality this situation did not arise. However, some interviews were brought to a conclusion because I recognised that the child was tired or experiencing pain, and it was deemed in the child's interests that the discussion should be ended. In some interviews, the children themselves indicated that they did not want to talk anymore, and these wishes were also respected. This kind of sensitivity to the child's situation is essential in research with children.

Measures were implemented to protect children's confidentiality and to ensure they were not coerced into participating in the study. In order to protect confidentiality, the names of children participating were kept separate from the data and were only associated with individual data records through a coding system. Rather than identify specific surgical conditions for each child, their surgery was described in more general terms. When I transcribed data from voice recordings, pseudonyms were used. There was the provision for references to children and families to be altered so that the integrity of the data remained, but there would be no means of identification. During the interviews, children were free to divulge as much or as little information as they chose. They were free to leave the study at any time without any prejudice to their current or future care. In the event of withdrawal, any data related to that participant, collected up to the point of withdrawal would be destroyed. No child withdrew from the study. The children and their parents were provided with careful explanation of possible risks; the type of involvement requested of them, and the expected time frame; and the arrangements for protection of confidentiality and privacy throughout the research activity.

Posteriori vulnerability refers to ethical issues that can arise during the conduct of the research (Tisdale 2004, p26). In this study, such ethically sensitive considerations were present whenever I entered the field. Some of the issues I needed to give thought to include:

- the appropriate time that I approached parents and children to discuss the study, so as not to add to the stress they were already experiencing through hospitalisation;
- instances where my duty of care to the child took priority over the role of researcher (such as the example of the concerns of the mother discussed on page 119);
- interviewing children when they were experiencing pain or discomfort, and responding appropriately;
- issues of confidentiality versus the choice of a familiar space for the children to be interviewed.

This section has outlined the measures that were utilised in the study to ensure ethical research conduct that was respectful of the children and that ensured their interests were met.

Study participants

Children aged between 6 and 12 years admitted for a surgical procedure to the paediatric unit of a general hospital were participants in this study. This section provides information about the study participants. There were 10 children who participated, five were male and five female. This equal ratio of males to females was not intentional, however the result was that there is equal representation and no gender bias. Table 4 provides information about the children who participated in the research.

Inclusion criteria for participants were that:

- children and their parents were English speaking;
- children were not involved in any other research study; and
- children with complex conditions or serious illness were not included in the study.

Table 4: Details of child participants

Participant	Age	Gender	Procedure	Previous surgery	1st interview	2nd interview
1	6	M	Abdominal surgery		5 days post op	Home
2	8	F	Abdominal surgery		Pre-op	Return visit to hospital
3	8	M	Urogenital surgery	yes	3 days post op	
4	12	F	Abdominal surgery		2 days post op	Home (phone)
5	9	F	ENT procedure		1 day post op	Home (phone)
6	8	F	Abdominal surgery		2 days post op	Home (phone)
7	7	M	ENT procedure		Pre-op	Home
8	10	M	Oro-facial surgery	yes	1 day Post op	
9	11	F	Orthopaedic surgery		1 day post op	
10	11	M	Major orthopaedic surgery	yes	Drawing and story only	

There was a spread of ages across the intended age range. The youngest child was 6 years old, the oldest was 12 years of age. Seven of the participant children had no previous experience of surgery; three children had previous admissions for surgery, and one of these three children had experienced several admissions for surgery or procedures relating to a urogenital condition.

There are no firm guidelines for sample size in qualitative research, however, the number of participants in this study is in keeping with other studies from this tradition, including studies with children as participants. These include, for example, Stewart's (2003) grounded theory study with 11 children aged 9 to 12 years undergoing treatment for cancer; Garden's (1998) grounded theory study with 10 siblings of children with chronic illness; and the study of illness experience with 7

children aged 7 to 10 years by Forsner, Janssen and Sorlie (2005) using qualitative content analysis.

Five of the children were to undergo non-elective surgical procedures, which meant the children had little or no time to prepare for their admission. The other five participants were to have elective or planned surgery, and this meant that these children had some time between learning of their need for surgery and their admission. The three children who had previous admissions for surgery were all to have elective surgery on this current admission.

The children came from a range of family situations. Some were from traditional family units, where they lived with both natural parents in one home. The parents of one child were separated and she lived primarily with her brother and mother, but both her parents were involved in providing care for the children, including during the period of hospitalisation. One child was a member of two blended families, and her natural as well as step-parents were involved in her care during her hospitalisation.

There were a total of 16 interviews conducted with nine children and 6 children did drawings, with 5 accompanying stories (the sixth, a younger child, aged 6 years, talked to me about what he had drawn). Nine interviews were conducted whilst the child was in hospital; two of these were in the preoperative period. The remainder of the interviews conducted during the child's admission were in the postoperative period, ranging from day one post-operation, to day five post-operation. One child was interviewed on her return to hospital for a routine check following surgery. Two interviews were conducted in the child's home following discharge. Three interviews were conducted by phone following discharge. One child did not wish to be interviewed for the research, but did want to contribute by doing a drawing and writing a story. This child had cerebral palsy, a mild hearing deficit and mild autism. Other children agreed to be interviewed for the research, but chose not to do a drawing or write a story. It was important to recognize and value the contribution of all the children who participated in the research, in whatever form they wished that contribution to be. The contribution of each child was equally valued. Younger children's voices were as important as older children's and the intent was to give a balanced representation of all participants in the rendering of the data.

I found that the children who participated in the research appreciated the opportunity to tell their stories (in whatever form). I also formed the opinion that they were quite serious in their approach to telling me what their experience was like, and in wanting me to understand their perspective.

The relevance of the research context

The research context influences the shape and design of the research, the methods and procedures and the application of the research findings. The research process is influenced by the space in which research takes place, but 'space is never an issue of mere location' (Barker and Weller 2003, p223) and is socially produced in a variety of ways. The centrality of context in research has associated political, economic, social and cultural dimensions. A 'goodness of fit' is required between the context, methods and approach to ensure contextualisation of research that can be recognised as credible, authentic and relevant (Kayrooz and Trevitt 2005, p3).

The interview context in this study included the nature of the topic for discussion, the purpose of the interviews and the physical spaces and social environments in which the interviews took place. Context was important when interviewing the children because expression of the personality can be dependent on the context (Scott 2000, p103). It was important to reflexively analyse how the research space impacted on the research process and the data collected (Barker and Weller 2003, p223). For example, some of the research environments were spaces where the children had little control (Punch 2002, p328), and where an interview was conducted influenced the ways the child responded. For instance, there was a risk that children's answers might have been influenced by the presence of parents or siblings (Scott 2000, p105).

The home and school are two of the most important socio-cultural settings for research involving children. The every-day-spaces where children's identities are made and remade can include the home, the school and the street (Barker and Weller 2003, p209). A way of overcoming power imbalances and children's shyness and embarrassment is by interviewing children in a familiar setting, such as their own home. Gaining access through the family home can be a very different process to gaining access through the hospital, as negotiation is with only one or two individuals, rather than the institution. Yet families are complex social groups, with

their own set of power relations and it may be that researchers' entering the private space of the home is seen as an intrusion by some (Barker and Weller 2003, p212).

Hospital represents an institutionalised space, designed and controlled by adults, where children have little or no control over what happens to them. Hospital is not an every-day socio-cultural space for children, but instead represents a foreign space for them. Even so, children actively contribute to and influence their own lives and the spaces that they occupy (Barker and Weller 2003, p209), and, although the space of the children's ward is one controlled by adults, children actively contribute to and influence this space. So you might consider the sights to be seen and sounds to be heard on entering a children's ward and compare these with the sights and sounds on entering an adult ward.

Interviews in this research were conducted in various locations, including the hospital setting and the child's home, as well as by telephone. Each of these carried with them specific considerations that I had to account for and reflect on.

The research setting – the paediatric unit

A description of the research setting serves to situate this study and draw a mental picture of the physical and socio-cultural space where the research took place (Figure 1 is a child's drawing of the study hospital). The Paediatric Unit was the physical location where much of the research was conducted and where the children spent the majority of their time whilst in hospital. Areas that were also part of their experiences included, of course, the Perioperative Unit, encompassing anaesthetics, theatres and recovery; and for some children, the Emergency Department. Children might have also attended other areas of the hospital as part of their experience, for example Outpatient Clinics and the Radiology Department.

The Paediatric Unit is a 24 bed specialist paediatric ward within a general hospital in the capital city of a southern state of Australia and children may be referred to the unit for treatment from across the state. The unit cares for infants, children and adolescents from birth to 16 years. The ward has a mix of single rooms and rooms with between 2 and 4 beds. Children are allocated to beds and rooms according to clinical need and bed availability, and during the course of an admission, children may be moved to different rooms. All of the patient rooms have large windows with

views to the outside. The children participating in this study were variously cared for in single, 2 bed and 4 bed rooms, and some children were moved to different rooms during their admission.

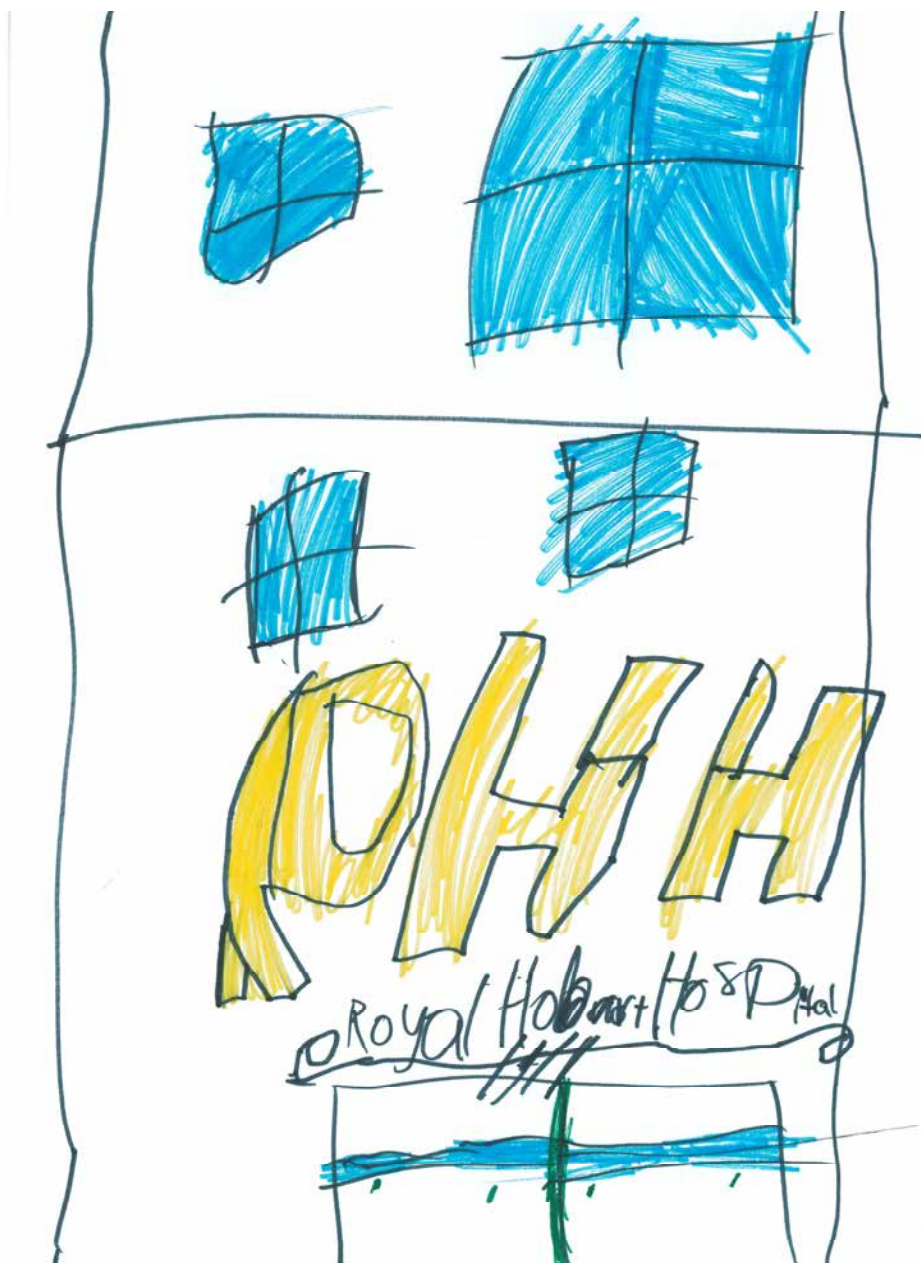


Figure 1: Drawing of the study hospital (Boy, 11yrs).

According to unit policy, a parent is able to sleep beside their child when safety and space permits. This means that parents are not normally able to sleep beside their child in the high dependency area, where children of highest acuity are cared for. In this instance they may sleep in another area on the ward, perhaps in the school room. Accommodation for parents who live a long distance from the hospital is available in separate facilities, in close proximity to the hospital. A number of the parents of children participating in the research slept beside their child's bed during their hospitalisation, others slept in the nearby parent accommodation, and others in their own home.

Nurses in the ward wear a uniform that consists of a range of coloured tops or shirts, and navy pants or skirts. Doctors in the unit do not wear white coats. In fact, the only staff members on the unit to wear white coats are the hospital clowns, called 'clown doctors'. There is a large staff of nurses with the unit. Children may be cared for by several nurses during the time they are in hospital. In addition, they will see numerous other nurses in other departments of the hospital, for example, Emergency Department and the perioperative areas. As well as the paediatric team of doctors, there are several other teams of medical staff they may be in contact with, depending on their illness or condition, for instance, the Orthopaedic Team and Ear Nose and Throat (ENT) team.

The ward has 2 play specialists who work a roster covering the 7 days of the week. A distance education school operates within the school term and school hours are from 0900 – 1200 Monday to Friday. Children may attend the school room, situated on the ward, or conduct school activities from their bed. There are ceiling mounted televisions over each bed space, and there is free access to these. There are also portable computer stations that can be wheeled to the child's bed space and children are able to play computer games, on these stations as well as 'Playstation' games.

It is generally a very busy unit, and children come in contact with a large number of people: as well as nurses and doctors, there are, for example allied health staff, support staff such as play specialists, teachers, cleaning and kitchen staff, orderlies and of course other children and their families and visitors. It can also be a noisy place, with the sounds of babies crying, people talking, the alarms from monitors and infusion pumps. Attempts to make it a bright and child-friendly space include use of

bright colours: the walls and floorings are in different colours and there is a variety of art works, including pictures by children who have themselves been patients. In addition, rooms are differentiated by the use of colour and shapes.

The hospital setting is a formally organised socio-cultural and physical space that has distinctive features that are quite different to many other environments familiar to children, such as the home and school and local neighbourhood. These differences include for example, the size of the buildings, the physical appearance of the buildings, medical equipment and different furnishings; the roles for those within it (including patients, families and staff); the forms of dress they wear (for example, staff wear special uniforms, such as surgical scrubs and patients wear pyjamas in the day time) and that even has its own language.

Conclusion

The ontological and epistemological underpinnings of this research are congruent with the research aims, design and the research methods. A qualitative approach emphasises understanding rather than prediction and the importance of meanings, processes and context. Constructivist grounded theory, underpinned by symbolic interactionism, guided the direction and procedures of the study. A symbolic interactionist perspective assumes society, reality and self are constructed through interaction and that interaction is inherently dynamic and interpretive (Charmaz 2006, p7). In constructivist grounded theory, the researcher is part of the world of study and the theoretical renderings are an '*interpretive* portrayal of the studied world, not an exact picture of it' (Charmaz 2006, p10). Understandings are created from shared experiences and relationships with participants.

The focus of this constructivist grounded theory research was the actions, interactions and social processes of the participating children. Children were viewed as social actors who are competent reporters of their lives and children's voices were at the centre of analysis. The incorporation of child centred research techniques allowed children's admission to hospital for surgery to be studied from the perspective of the participating children.

Commitment to meeting the ethical requirements for conducting research with children was essential to the study. The development of assent documents with

children ensured the research was presented to the children in a form they could understand and demonstrates the commitment to respecting children's rights.

The next chapter focuses on the research methods used based on the purpose of the study.

Chapter 5: Data collection and analysis

Grounded theory studies emerge from wrestling with data, making comparisons, developing categories, engaging in theoretical sampling, and integrating an analysis (Charmaz 2005, p510).

This chapter continues on from the previous by providing an account of the methods of data collection and data analysis used in the study. The methods that were utilised needed to be appropriate for research with primary school age children, and so the chapter begins with outlining child centred research techniques. The chapter also details the sources of data used in the study: interviews with children around the time of their surgery; participant children's drawings and stories about their hospitalisation and surgery; my own observations from the field; and how the literature was used as a data source.

Child-centred research techniques

It was essential that the complexities of the epistemological and methodological questions inherent in research with children were acknowledged in this study. Because the research directly involved children, the research design needed to be specifically appropriate for children of primary school age and practices that resonated with the children's own concerns and routines were required (Christensen and James 2000, p7). In addition, the methods needed to be appropriate for the context; the framing of questions; and the production and interpretation of the data. Recognising children as social actors in their own right and forming relationships so that children wanted to participate in the research was combined with respect and insight around the theoretical, practical, moral and ethical issues that are a part of research with children.

Methods that lent themselves to research with children aged 6 to 12 years were used. Factors that were taken into consideration included the age of the individual children; their general cognitive ability; emotional status; specific knowledge at the time of the research (including experience); what I was asking of them; and the research setting (Lindsay 2000, p4). The use of different and flexible methods of communication that included drawings, written work and oral communication, were designed to take into account the children's different abilities and competencies; served to increase the

children's control over how they wanted to contribute to the research; and aimed to increase my engagement with children (Garden 2007, p22).

In recognition of their unfamiliarity with the process of a formal face-to-face interview, interviews were at times conducted within the context of, or alongside everyday activities (Davis 1998, p328). Including activities enjoyed by children, such as games, story telling and drawing were some ways of bringing out the complexities of the children's experiences (O'Kane 2000, p140). Such approaches enabled the children to be active participants in the research process. The draw and write technique was one child centred method used in this study. The technique had a significant impact in furthering understandings but, as will be discussed later in this chapter, its use was not unproblematic.

Because the children were recognised as being potentially vulnerable to persuasion and adverse influence, they needed clear explanations about their involvement in the research without placing pressure on them. In order to minimise the effect of my own authority, I used techniques such as informal language and I was conscious of positioning myself at a comfortable level for the child when conducting interviews (Hill 2005, p63), such as sitting at a low table with low chairs or on a chair beside their bed. I sought to ensure questions measured the desired concept, that questions were unambiguous and that the children were able to interpret the questions as intended. Questions needed to be pertinent and relevant to the child's experience or knowledge. The child's motivation to provide careful and truthful answers was acknowledged as being dependant on the rapport established between the child and myself as well as addressing possible power differentials (Scott 2000, p107-109).

The relationship between the participant children and myself as researcher

The vulnerability of children and the inherent power relations between us meant that I needed to ensure the children did not suffer any harm or adverse effects from their involvement in the research. Power relations needed to be acknowledged, both ethically and practically. Approaches that avoided undue pressure to participate in the research or undue intrusion, and methods that were non-invasive and non-confrontational were some ways of addressing the issue of power imbalance. It was also important to be aware of the emotions of the children and the pressures they may

have experienced, for example, fear of failure, threats to self esteem, invasion of privacy, conflict, guilt or embarrassment (Davis 1998, p328). As a researcher conducting a study involving children, I sought to empower them, to understand their emotions and recognise their fears (Davis et al. 2000, p213). Further, I sought to start from the perspective of the children (Hill 2005, p63). The aim was to form relationships where children wanted to participate in the research and so feel they had a sense of control, and this was seen as another way of empowering the children. In addition, the power imbalance was addressed by utilising a number of techniques that aimed to increase the children's sense of participation and control in the research process and served to assist in establishing effective communication with the children (O'Kane 2000, p140). Acknowledging the power differences presented a more effective way of addressing those differences than ignoring or disguising them. Implicit in meeting this challenge was the development of reciprocity between myself and the children and the explication of the power imbalances in these relationships (Mills et al. 2006a, p9).

The stance taken in the current study is that I asked children directly to help me, an adult, to understand their experience: I wanted to investigate directly with children the knowledge they have of their admission to hospital for surgery. I wanted to acquire from them their own unique knowledge and assessment of what it meant for them to be engaged in that experience. I presented myself as a person, who as an adult, does not have this knowledge (Mayall 2000, p112).

Sources of data

Data was collected using a number of methods, including interviews with children, the draw and write technique and my own observations in the field. Literature was also recognised as a source of data, as is consistent with a grounded theory approach (Stern 2007, p123, Charmaz 2006, p166). The detailed narratives from transcribed interviews, the stories and drawings of the children and field notes of observations, provided 'thick' descriptions. The aim was to obtain rich data, that was detailed, focused and full and that would provide solid material for significant analysis. Rich data reveals the participants views, feelings, intentions and actions as well as the contexts and structures of their experiences (Charmaz 2006, p14). Each data source

contributed to my understanding of children's admission and surgery from their perspective.

Constructivist interviewing with children

In constructivist interviewing, the participant is at the centre of the interview. Constructivist interviewing acknowledges the interview to be a meaning making experience and a place for knowledge production through the active collaboration of the interviewer and interviewee (Hiller and DiLuzio 2004, p3). It is about 'the establishment of a human-to-human relation with the respondent and the desire to understand rather than explain' (Fontana and Frey 2005, p706). Constructivism stresses the dialogic character of the interview and the mutuality of the research experience. Conventionally, interview respondents are viewed as passive 'vessels of answers' for questions posed by interviewers, and as repositories of facts, feelings and experiences (Gubrium and Holstein 2003, p31). Convention has required the interviewer to be careful in the way they ask questions, and to be neutral and non-directional in order to prevent bias or contamination of the interview. In other words, interviewers have been required to keep their 'selves' out of the interview (Gubrium and Holstein 2003, p31). However, the interview is not an unproblematic neutral tool. There is an asymmetric nature to it where the interviewer is an individual historically and contextually located, bringing both conscious and unconscious motives, desires, feelings and biases. Researchers are urged to be reflexive about what the interview accomplishes as well as how the interview is accomplished, and therefore the way that text is created. For it is the researcher who 'ultimately cuts and pastes together the narrative, choosing what will become part of it and what will be cut' (Fontana and Frey 2005, p696).

Quality data is constructed in the interview through the interviewer's use of self; of relationship building; through an awareness of the flow of conversation; and a sensitivity to theoretical and professional positions as well as the research question. The skilled interviewer 'uses his or her person to communicate with people to create stories' (Nunkoosing 2005, p698). In grounded theory, constructivist interviewers are considered 'part of the world we study and the data we collect... [and that]... we construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices' (Charmaz 2006, p10).

My reflections on some of the experiences and positions that I brought to the research are discussed in Chapter 1 - that I am an experienced paediatric nurse, a nurse educator in this specialty and I am the parent of children who have undergone surgery.

In research with children as participants, constructivist researchers consider children as subjective, contextual, self-determining and dynamic beings (Greig et al. 2007, p48). As children interact with others, they construct joint meanings within a specific context. Constructivist researchers attempt to understand how the worlds of children operate, by getting as close as possible to those worlds, 'describing and analysing the contextualised social phenomena found there' (Greig et al. 2007, p48). In this research, interviews were considered to be a collaborative communication, and an 'interactional co-construction' (Gubrium and Holstein 2003, p33) of meanings that is a discourse between myself as interviewer, and the child. The statement by Mischler (1986) provided a frame for my approach:

The discourse of the interview is jointly constructed by interviewer and respondent... Both questions and responses are formulated in, developed through, and shaped by the discourse between interviewers and respondents... An adequate understanding of interviews depends on recognising how interviewers re-formulate questions and how respondents frame answers in terms of their reciprocal understanding as meanings emerge during the course of an interview (cited in Gubrium and Holstein 2003, p35).

The interview was not seen to be a neutral exchange of my asking questions and getting answers. Rather it was viewed as a process where my exchanges with children participating in the study led to the creation of the collaborative effort – the interview (Fontana and Frey 2005, p696).

The interview process

Inherent in this research with children is the recognition that as an adult researcher, I was not able to completely share children's perceptions and understandings, partly because, as an adult, I am constrained by my own 'adulthood'. My adulthood in this instance presented an element that shaped the interview and filtered knowledge (Fontana and Frey 2005, p712).

Sometimes children's answers indicated different understandings within the same interview. In certain instances, careful use of interview techniques such as repeating

a question at another point in the interview, helped to clarify the child's meanings. There were differences in children's individual 'performance' in interviews. For example, there were occasions when children's responses were found to reflect inexperience rather than incompetence. In addition, the child's responses in interview were contextually situated (Westcott and Littleton 2005, p146). The following quote is taken from an interview with a child before her surgery for appendicitis.

I: Can you tell the story about being in hospital?

C: Ummm, Well, I don't really know

I: What happened when you came to hospital... tell me about that

C: Scary

I: It was scary? What were you scared about?

C: Umm, I don't know

I: Were you worried about something?

C: Mm...(Girl, 8yrs)

The child said she 'doesn't know' in answer to some of the questions I asked her. This interview was conducted in the preoperative period, when the child was frightened and in pain and her responses need to be considered in this context. The following excerpt is taken from the interview conducted with this same child after her surgery. It presents her response to a similar question that asks the child to talk about what it is like being in hospital:

I: Can you tell me about being in hospital. Can you tell me a story about it?

C: Well I didn't like being in. But when my cousin Holly came in every time when she came in she, I looked much more better, I did when she came in. So mum and dad called her Nurse Holly because she always makes me better when she came in (Girl, 8yrs).

In this excerpt, the child was able to answer the question in more detail, but this does not make this answer more correct than the answer she provided in the first interview. The child had the experience of hospital and surgery to draw on and she was now well and not frightened or in pain. Her experience and the context clearly made a significant difference to her response.

This does not mean that some questions, situations or contexts are better at revealing competence or understanding than others. Interviews are psychological spaces requiring attunement to others. The researchers' interpretations of what counts as 'good, correct or appropriate' responses will most likely result in a failure to fully

recognise the meanings of children's responses (Westcott and Littleton 2005, p147). My task therefore was to explore the responses of the children in order to achieve a greater understanding of each child's perspective and ask throughout the interview 'what is the child making of this?' My thoughts when analysing examples such as these responses led me to think about the changes in understandings that the children demonstrated and talked about. Their process of moving from 'not knowing' to 'knowing' became an important part of the analytical conceptualisations, described in detail in the findings chapters.

The research acknowledged that even young children are reliable reporters of their experiences and that children have the right to be involved in any decisions concerning their health care. While recognising their right to participate, it was also important to find ways to hear the voices of children that did not cause them harm or distress. It was important to consider the emotions that the interviews might elicit, the perceived threat that the interviews might present and any form of coercion that may arise. In interviews, children felt unwell, they experienced pain, and they said they were scared. Sensitivity to, and responding to the child's needs was the priority. It was important to acknowledge the children's feelings and to be careful not to cause further stress through the process of interviewing, so an interview may have been quite brief, terminated or postponed.

The following memo describes an issue that arose in the course of one interview:

Memo

8-year-old Bec (psued) was to go for laparoscopic appendicectomy the day of our interview. On the verge of tears, Bec told me that she was scared and she didn't know what was going to happen. One recommendation for this kind of situation is that the interviewer continues the interview, then revisits concerns such as those expressed by Bec at the end of the interview. But what was in Bec's interests? We talked about the procedure, at the same time as alarm bells were ringing in my head about 'recommended interview practice' 30.8.2006.

In constructivist interviewing, there is a collaborative communication between the interviewer and participant, and this memo extract provides an illustration of such a discourse between the interviewer and the child. Charmaz (2004) has also described temporarily abandoning the researcher role, when she has validated participants. Charmaz gives as an example 'when a young man who was depleted by dialysis

berated himself for not getting enough done, I told him that I thought he accomplished a great deal' (p985).

Children were found to be keen to participate even though there was no direct benefit to them in doing so. One interview I conducted was with a boy who was recovering from appendicectomy. The child's mother had thought he would want to finish watching the television program that he was enjoying before commencing the interview. However, the child wanted to start the interview immediately. On another occasion, though, the boy told me he asked the ward's visiting clown doctors to go away because he thought they were a bit silly really and he wanted to watch the television at that time. I think this child was clear in indicating when his viewing of the television could and could not be interrupted by interview or clowns....

A recognised way to commence a qualitative interview is to ask: 'Tell me a story about...' (Morse 1995, p147). I found that the younger children were less able to, or less comfortable with answering a number of open-ended questions like this one. Just as others have reported (Irwin and Johnson 2005, p824), I found that there were often times when closed or direct questioning elicited more detailed responses from the children. The linguistic abilities of children mean that they are sometimes unable to deal with the complexities of open-ended questions in the absence of other verbal prompts or cues. I used 'wh' type questions such as 'where were you?' and 'what happened next' that request particular information, in contrast to utilising 'yes/no' questions that simply require confirmation or disconfirmation.

Typical representations of qualitative interview transcripts are solid blocks of text that represent the voice of the participant and that includes limited lines from the research interviewer (Irwin and Johnson 2005, p825). However, when children are interviewed, this assumption may not be met. As can be seen in the excerpts from interview transcripts included in this work, there was a necessary alternate structure used in interviews in this study because children were the research participants. This structuring of interviews resulted from the prompts and direct questions that were a necessary part of the interview process and that was in acknowledgement of the verbal and cognitive abilities of the participating children (Irwin and Johnson 2005, p825). The intention of the research was for the words of the participating children to

be given prominence, but my own voice is also present in the excerpts, to such an extent that would not usually be seen in qualitative research with adult participants.

In this research, the choice of interview location was determined by what was believed to be in the best interest of the child rather than issues like sound quality or convenience of the interviewer. In an attempt to give children control over their participation in the research, children determined as much as possible when interviews took place; and interviews in hospital were conducted in what are acknowledged as 'safe spaces', such as the child's bed space, the play room or school room. Once again the children would participate in choosing the location. In their home, the children chose where they would be interviewed in agreement with their parents. In addition, children chose whether their parent would be present during any of the interviews. Interviews in the child's home took place in a parent bedroom and in a sibling's bedroom, and as stated, these locations were decided upon by the child in collaboration with the child's parent. Out of sensitivity to the children's position and an awareness of what constitutes appropriate behaviour on my part, the door to the bedrooms was left open. I was cognisant of the fact that as researcher, I was in the privileged position of entering into the homes of the children and their families as their guest.

These locations were not in keeping with other conventional recommendations for interviews to be conducted in private areas, such as formal interview rooms, where interruptions and distractions are unlikely. In fact, I experienced situations relating to the interview space that I needed to reflect upon. For example, interruptions and distractions occurring during the course of interviews included the alarm of the infusion pump, the nurse inquiring as to the child's wellbeing, and a visit by the maintenance man (!) in the hospital setting. In the home, curious siblings came in to the room the interviews were being conducted in, or normal household routines impacted on the conduct of the interview, for example, the serving of afternoon tea after arriving home from school. In addition, the children themselves were occasionally distracted by things going on around them. Initially, these interruptions presented a challenge, but I came to accept these realities and to work with them. This is recognised as important and necessary parts of the child's context. Rather than trying to control the environment, these events form the context of the child's

social world. By altering the environment the child's process of finding authentic voice may be hindered (Irwin and Johnson 2005, p825). Multiple interruptions, building rapport, consent and confidentiality and power and control are issues identified in research with children by MacDonald and Greggans (2008, p3123). The memo below outlines my thoughts during the period of conducting interviews about these aspects:

Memo

Sometimes children would change the subject and begin talking about things completely outside of the surgery and hospitalisation and they would become quite animated in these discussions. For example, Ned (pseud) talked to me about his basketball playing; how his team was going really well in the competition; as well as the number of goals that he had scored in recent games. He also talked about his favourite teams in the national football league and the recent grand final. These were important things in his life that he wanted to relate to me and it was important for me to listen to them and respect them and engage with him about these things 16.4.2007.

Interactions with the child that included discussions about topics quite removed from the subject of the research were essential in order for the child to 'be himself' and to increase his feelings of comfort and control. These also served to provide a sense of the child's progress since his admission and surgery, and how his experience of surgery was only a part of his world. The child had experienced a minor complication following his ENT surgery that resulted in his refusal to eat or drink for a period following discharge from hospital. Through his discussing other 'important' activities, such as his progress in basketball, I was able to understand that despite the difficulties associated with his surgery, he had moved on or 'bounced back' from the experience. This deeper understanding of his experience of surgery would not have been possible if I had simply attended only to what he had to say about his admission and surgery. I found that all data was relevant to my understanding.

In some interviews children had a level of shyness or initial discomfort as I was both a stranger to them and an adult. The initial discomfort children can have in interviews for research activities has been described in the literature (Christensen 2004, p168). I needed to reflect on their reticence and how it could be alleviated. The building of rapport and trust was essential to the relationship with the children and additional time was spent in gaining a rapport with the children as is recommended in qualitative research (Irwin and Johnson 2005, p825). I found that when there were

subsequent interviews, the children were not shy or reticent and believe this was due to the fact that they had come to know me a little and therefore trusted me. Again this familiarity and trust in subsequent interviews has been described in the literature (Christensen 2004, p168).

Building rapport with the children entailed participating in some interesting activities with them such as talking about things like sporting activities and interests (as described in the previous memo), playing with them and other family members, or sharing hospitality (Appendix 7 is a memo from one visit to a family's home). One example of building rapport was assisting a child with a school work sheet provided by the hospital teacher, whilst her mother read the consent document. On another occasion I participated in the child's visit from the hospital clown doctors. This involved a 'mock interview' conducted by the clown doctors, a song that they sang to the child and being wrapped in a sling made of toilet paper so that I too could have a 'broken arm'.

The interviews ranged from approximately 15 - 30 minutes, but time was also spent with the children in activities as described above. Interviews were tape recorded, and in some instances the children enjoyed having control of the tape recorder. They were interested in hearing the sound of their voice on the tape when sound checks were made. The possible distracting or inhibiting effects of the use of a tape recorder was given some consideration. The children did not indicate that they were disturbed by the device, and seemed to ignore it during the course of the interview. This observation reflects the findings in other research with children (Coyne 1998, p413). Following each interview I made notes about the interview that detailed relevant information including the child's age, surgical procedure, previous admissions, date and location of interview and key points. In addition, I made memos that explored in more detail my thoughts and reflections on each interview.

Conducting interviews by telephone was a method that required a level of careful consideration. This form of communication can be more natural for people than more formal interview situations and the 'friendly conversation' may be easier to achieve on the telephone than through other ways (Grbich 1999, p102). In this age of increasing communication by mobile phone, many children of school age, as well as adults are quite familiar with this communication medium. Telephone interviews are

most effectively used as a second interview, following initial face-to-face interviews. This can be because in this situation, the person being interviewed has already met the interviewer, and there has been an opportunity to establish some rapport (Grbich 1999, p102). In this research, phone interviews were subsequent to the initial interviews conducted with the children in hospital and so the children had already met me in person. The decision for a phone interview was made in collaboration with the parent and child and was largely for the convenience of the child and family and to fit in with the busy schedules of the families. The children I spoke to by phone indicated their readiness to talk to me at the commencement of our telephone discussion and were animated in their conversation and these interviews provided valuable data for the study. I found that one aspect of these conversations was different to the face to face interviews, in that important visual cues around body language and nonverbal communication, inherent to face to face interviews, were lost in this form of interview.

Another very important consideration in the choice of space for conducting interviews has to do with ensuring confidentiality for the children. However I found that sometimes working to ensuring children's confidentiality conflicted with other considerations when interviewing. Within the hospital, the child's bed space does not offer the level of privacy of an interview room. However, finding a private or quiet space in the home can also be problematic (Barker and Weller 2003, p215). Some parents, who were not present during interviews, also expressed an interest to learn what their child had to say about their experience, so that they could further understand the impact that hospitalisation and surgery had on their child. It was necessary to reconcile this request with the need to maintain the child's right to confidentiality. However, there were times when parents were present when the children were interviewed. Whether the parent was present or not during interviews was the decision of the children, in collaboration with their parent.

Interviews were brought to a conclusion by the children themselves, or by me. For example, in one interview, I saw that the child was tiring, so I brought the interview to an end. One child, who had enough of answering questions and who now wanted to play asked:

Can we hop off now?(Boy, 8yrs).

Parental presence and the interview process

The presence and attitudes of parents can have a significant influence on the interview process. Some of the reasons for this identified in the literature include the following: Interviewers might prefer to interview children away from their parents in an attempt to standardise interviews and the data created (Alderson 1993). Parental presence may also inhibit the child, as the child may want to protect their parent from emotion-laden information and negative feelings that the child may have experienced (Docherty and Sandelowski 1999, p181). In addition, children may not be as frank if parents are present (Scott 2000, p110). Alternatively, parental presence can help foster a safe and secure environment for the child, and of course, the context of young children's natural interactions frequently include the support of their parents (Irwin and Johnson 2005, p828).

In this research, the child and the parent decided if the parent was to be present during the interviews. This was in order for control to lie with the child and parent and was in recognition that asking parents to leave could have implied a position of authority on the part of the researcher. This in turn may have created an inhibiting relationship that would adversely affect the level of trust and rapport between the child and interviewer (Alderson 1993, p72). My experience was that parents generally stayed close to their child when interviews were conducted during the hospital admission. Perhaps this was because parents are vigilant and 'on guard' whilst their child is in hospital, and their presence at interview provided necessary emotional support to the child during the stressful period of their admission. When interviews were conducted after discharge, the parent was not present. This may be because the child was feeling less unwell, or fully recovered, and may also reflect the child and parent's confidence and familiarity with me, and the rapport that had been established in our earlier interactions. Another influencing factor could be because the children were in their own homes they were in an environment where they felt comfortable.

In the consenting process, parents were told that the aim of the study was to explore the child's understandings. Parents understood that the focus was therefore on what the child had to say, so during the interviews parents generally listened attentively, but did not attempt to 'speak for' the child. However, it was also recognised that parents of younger children may assist in the scaffolding of the children's stories by

using prompts such as, for example, ‘remember when...’ or ‘what did you tell me the other day about...’ (Irwin and Johnson 2005, p827). This scaffolding was seen on a number of occasions in the interviews and assisted in furthering understandings. One example of scaffolding was when a mother reminded her son of what he would say to her when he was undergoing induction of anaesthetic:

Mother: You say bye bye to me, don't you?

C: (nodding) 'Love you mummy bye bye' and then you're asleep (Boy, 8yrs).

The importance of the parents' role in the research was seen to influence my own approach, access to the child and the content of the interview.

To summarise this section, interviews with children required that I took into account individual children's development – their language and cognitive abilities and accommodate for these in the research. Conversations with different children reflected the different ages and experiences of the children. So that children's responses to questions were at times seen to reflect inexperience rather than competence, and sometimes children of a younger age were able to provide detailed responses to questions, reflecting their experience. On occasion, careful questioning was needed to elicit a child's meaning, using prompts or direct questions. Parent's presence in interviews provided emotional support to children and sometimes resulted in further understanding through the use of scaffolding. Respect for children's needs and contexts meant that interview settings were often different to those that might be used with adult participants. All these aspects reflect considerations for children's development in the interview process.

The place of story

Story had an important place in this research and stories were elicited through both interviews with the children as well as through their writings and drawings. Stories reflected the children's understandings of their situation and their efforts to shape views, of self, situation and others. Story formed a part of constructivist interviewing with children in this research, considered in the previous section, and in their use of the draw and write technique, considered in the following section. Story is a way of understanding oneself-in-the-world (Engel 2005, p208) and are renderings of reality (Charmaz 2002, p311). Story has an important place in nursing and within paediatric nursing in particular (Carter 2009, p477). Stories are accounts of happenings, they

are dynamic, and formed and reformed through experiences and the contexts in which they are told and by the responses they elicit. According to Carter (2009), through their stories we can learn of children's fears, anxieties, achievements and hopes:

Good stories, in the clinical sense are not predicated on an extensive vocabulary or being able to draw on a particular form or structure. Good stories are ones where the child's story tells us something which we might not have known before, or reminds us of something to which we should be paying attention. Stories can give us access to children's subjective experiences of illness. Stories can provide a way in for us to understand something of their lives and their explanatory frameworks which may be very different to our own...

The stories that sick children tell are stories about themselves and their experiences, their anxieties, fears, hopes and triumphs (p477-478).

The children's stories allowed the human and personal aspects of their experience to be captured and they gave an understanding of how the children thought about their world that was hospital and surgery and how they made order of that world. In their stories, the children looked for a sequencing of events that made sense for them. The children's narratives about their experience provided information about their complex feelings and responses to their illness, diagnosis, surgery and interventions.

In interview, stories are both process and product and how the researcher is viewed by the participant influences the story told, so a receptive listener elicits stories (Charmaz 2002, p323). The value of listening to children's stories cannot be overestimated and health professionals are able to learn a great deal by taking the time to listen to children about their experiences. The children were encouraged to tell their story openly and to decide what was important to them and their responses were not limited by a fixed agenda (Carney et al. 2003, p28).

Children's drawings and associated writing

In this study, children's art and written work were seen to provide significant methodological possibilities that could increase understandings of how the children saw their world. Asking children to draw images and do writing that depicted and outlined their ideas about their admission to hospital for surgery was one way of working toward this.

The draw and write technique is a recognised method for exploring the meanings of health and illness with children. The technique was used in the research to obtain quality, child-centred data that incorporated children's 'ideas, beliefs and metaphors' in the research process (Pridmore and Bendelow 1995, p473). The technique was an important source of data that led to increased understandings of how the children saw their admission to hospital for surgery.

The technique is primarily a qualitative tool for understanding how children explain and construct ideas and concepts. Children are invited to draw a simple scenario and to write what is happening. The technique is suitable for children as young as 4 years because adults can act as scribes for younger children. The technique was initially developed as a tool for curriculum development but is increasingly used in research into children's perceptions of health issues (Wetton and McWhirter 1998, p273).

Children are familiar with communicating through drawing and story as: 'children create order, solve problems and make sense of the world through their drawing as through their language' (Alderson 1993, p70). In this study, drawing and story aimed to allow the children the freedom to express their views, imagination and their interpretations of their experience, in their own terms. The power imbalance between adult and child could also be reduced as the child was in control in creating the drawing and story (O'Kane 2000, p140).

Origins of the draw and write technique

Children's drawings have been viewed as 'coming from the world of the child' and reflect their inner emotions. Drawings have been used as guides, to reveal information that was considered too difficult for the child to talk about, or to assist communication between adults and children. The use of children's drawings in studies are found in psychology, anthropology, geography and art therapy (Backett-Milburn and McLie 1999, p388). In addition, children's drawings have been used for a variety of health studies, including research, clinical diagnosis and therapy. The ways drawings have been analysed have been influenced by epistemological positions and assumptions around what the drawings are deemed to represent (Backett-Milburn and McLie 1999, p389). According to Vygotsky, children from around 7 years begin to master the symbolic meaning of drawing (cited in Veale 2005, p253).

Studies that have utilised this technique with children include health promotion studies; the study of children's views of themselves and their social world; and the health beliefs of primary school age children. It has also been used to explore children's beliefs about specific illnesses and their aetiology, including cancer (for example Oakley et al. 1995, Wetton and McWhirter 1998, Pridmore and Bendelow 1995, Rollins 2005). In a grounded theory study by Rollins (2005) on children's coping with cancer treatments, children's drawing were found to enhance communication through both visual and verbal expression. In another grounded theory study by Sartain et al (2000) around children's chronic illness, drawing was a practical way of bringing children into the interview situation and of encouraging them to talk about themselves and their experiences. The draw and write technique has been used in a number of different settings, both as a stand-alone task, and as part of wider set of research methods.

Strengths and limitations of using children's drawings

Using images that children draw has a number of strengths. They can provide a personal starting point for interviews with children to explore understandings (McWhirter et al. 2000, p204-205) and they can help children to relax and concentrate their thoughts, to reflect before expressing themselves. The draw and write technique can allow children to express through drawing ideas they may not initially have words for, and then seek assistance to write about these ideas. The technique has the potential to give insights into children's perceptions and can allow the child's lived experience to be represented, increasing our understandings of how they interpret their world. It also has the potential to enable participation of young children, children with special needs and those who cannot read and write (Pridmore and Bendelow 1995, p486). The draw and write technique provides one way of accessing children's conceptualisation of health-related issues, and for children to have their own ideas expressed and understood.

Limitations and concerns over the use of the technique have also been identified and the use of drawings as primary data has been questioned. Some depictions can be more abstract, and when children are asked to draw complex concepts, meanings can become more ambiguous. There is then a danger of over interpretation of meaning from children's images especially when pictures are more symbolic (Wetton and McWhirter 1998, p274). Caution needs to be used when analysing drawings as they

are seen as more ambiguous than written (or spoken) comments (McDonald and Rushforth 2006, p34).

Drawing is usually seen as an enjoyable, participatory activity that all children can take part in. However, there should not be an assumption that drawing is an easy option for every child. It is argued that the technique does not reflect the complex development of drawing skills among children. Picture making necessitates knowledge and there is the risk of assuming that drawing is simple for children:

[There is] a naïve tendency... to regard children's drawings as if they are direct translations of mental states and images onto paper... drawing is not an easy skill to acquire... young children generally become more skilful in their drawing as they grow older and more practised (Thomas, 1995 in Backett-Milburn and McLie 1999, p390).

The use of the draw and write technique in this research

At the time of interview, children were asked if they would like to do a drawing. All of the children were given a pack of coloured felt pens to keep and sheets of blank A4 size plain paper. Copies of their drawing were later sent to the children with the letter thanking them for their participation in the research. Children had the opportunity of choosing when they did their drawing: some did their drawing at the time of the initial interview; others wanted to do their drawing later, either whilst still in hospital or following their discharge when they were at home. Children were given a stamped addressed envelope to return the drawing and story in should they chose to do these following discharge.

Not all children chose to do a drawing or write a story. It was also apparent that not all children were comfortable with doing so and whilst there were important understandings gained through the use of this technique, there were some limitations associated with its use.

A drawing by one of the participant children follows (Figure 2). The drawing is incomplete, and my thoughts were that the child was not happy with his attempt to provide a drawing. We recall that drawing is usually seen as an enjoyable, participatory activity for children. Here it seems that drawing is not an easy option for every child. This child wanted to participate in the study - in fact he was very eager to talk to me about being in hospital and having surgery. During the interview

he was animated and interested, and when asked, readily agreed to do a drawing. He said he would do the drawing after the interview and it would be returned to me in a self-addressed envelope. It was not possible therefore to check my interpretation of the drawings with this child.



Figure 2: Incomplete drawing (*Boy, 8yrs*)

The next picture is another provided by the child. This picture was drawn by an adult (his mother) and is of a nurse in hospital scrubs. The written text accompanying the drawing has been taken to represent the child's thoughts about the nurse who cared for him in recovery, transcribed by his mother.

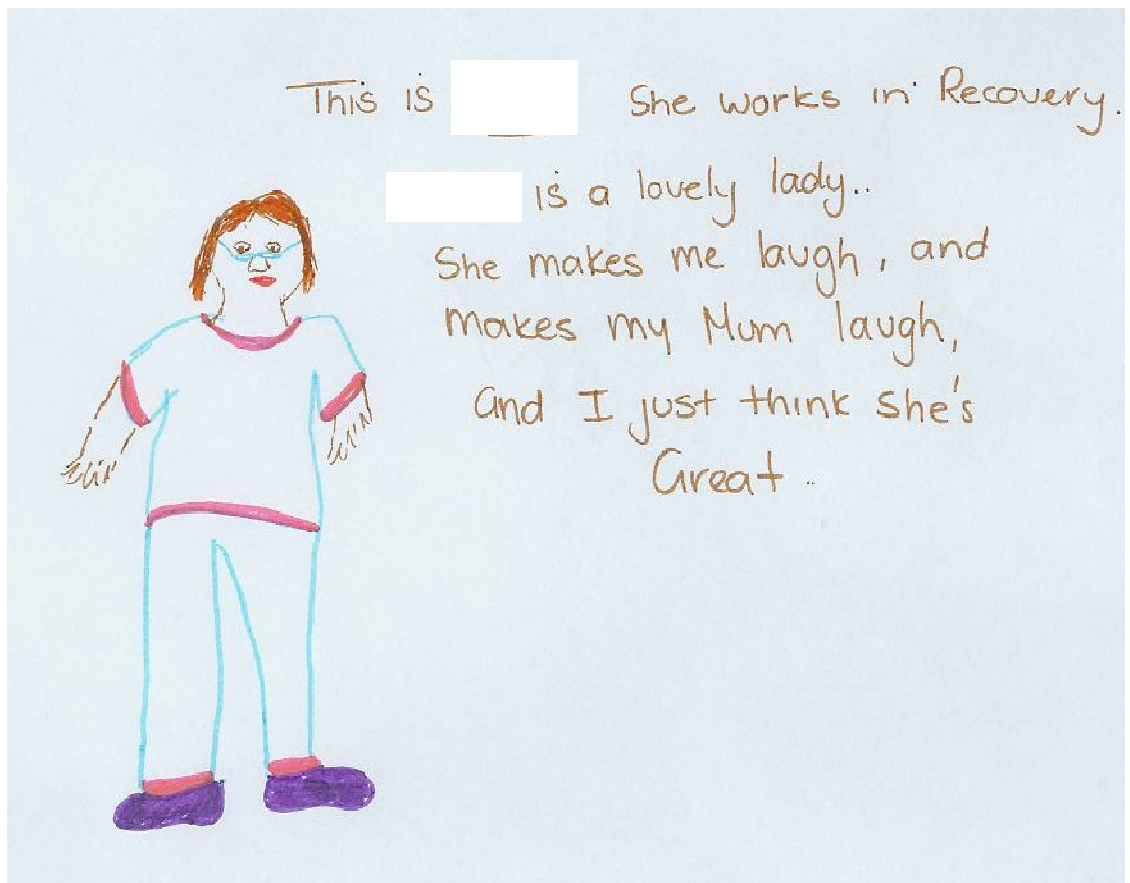


Figure 3: Drawing of recovery nurse (Boy, 8 yrs)

I needed to reflect upon how I addressed this issue and utilised this data. I thought about not including it at all, because the drawing was not by the child. However, that would not be respectful of the contribution by this child, nor would it be consistent with my intention to value the children's contributions to the research in all their forms. These drawings helped to further my understandings, and were important and valuable to the study. For example, it provided an example of the supportive role played by parents of children. Further, it indicated the importance the child gave to knowing the name of the nurse caring for him, as well as the importance of the use of humour in the nurses' interactions with the child. These were concepts that were further developed in analysis of the data. These drawings also made me reflect on the difficulty some children had with different forms of contributions to the research, while still wanting to participate in the study.

Overall, the children's drawings and the accompanying story (written or verbal) provided a rich and meaningful insight into the children's experiences and the ways

they viewed and made sense of them and served to increase understandings of the phenomenon of their admission for surgery.

My own observations from the field

It might be useful to shift from a concentration on observation as a 'method' per se to a perspective that emphasises observation as a context for interaction among those involved in the research collaboration (Angrosino 2005, p732).

Observation provided further information on the children's real-life experiences of admission and surgery as well as their reactions to those experiences and my own observations of children formed an important source of data. Through observation, information was gathered about the physical environment they were in, particularly when they were in hospital; the activities they engaged in whilst in hospital; their social interactions and roles; and the children's own actions and choices in the context of those activities. Observation permitted insights into the meanings for the children of activities that were going on around them and their interactions with others in those activities (Tudge and Hogan 2005, p103).

As an adult, I was not able to conduct observational research as a full and participating member – as a participant in a group under equal conditions with children, because once again I was constrained by my adulthood. In this study, participant observation was used to assist in exploring the processes the children were engaged in. Participant observation is an activity (that can be either covert or overt) where the researcher participates in the daily life of the people under study, observing things that happen, listening to what is said and questioning people.

The fact of being observed can result in a change in behaviour and the phenomenon of altered behaviour or performance resulting from an awareness of being observed has been termed the 'Hawthorne effect' (Greig et al. 2007, p40). One way of limiting this risk is by making multiple observations and in the current research, numerous observation periods were conducted over the course of the research, in various settings. Observation periods included observation of children in the perioperative setting, including their admission to the perioperative unit, induction of anaesthetic, operative procedures and the children's recovery from anaesthetic. In addition, there were periods of observation associated with the interviews conducted whilst the

children were in hospital as well as those conducted in their homes. Throughout the study, I maintained field notes of the observation periods, my contacts with the children and their parents and my reflections on the interactions and the data.

In a study by Coyne (2006b) involving hospitalised children, the researcher discussed how she familiarised herself with the research setting by undertaking periods of observation prior to commencing data collection. This was in order to become familiar with ward layout, daily routine and staff (p63). As a clinical nurse I had previously worked in the paediatric unit where the research was based and as a nurse educator currently attached to the unit, I was well familiar with these aspects of the unit, so observation for this purpose was not necessary. In contrast, however, I needed to reflect on the possible impact my close affiliation with the research setting might have. One possibility was that because I was so familiar with the research setting, I might overlook some of the taken-for-granted practices that impacted on children's experiences, so reflexivity was again recognised as important in the research process. In addition, I followed a number of processes when entering the unit for the purposes of observation and interviews with families, as discussed now.

These activities were undertaken during a period of extended leave from my position. On the paediatric unit, I wore civilian clothes, rather than nurses' uniform and wore my university identification tag, rather than the hospital issued identification. In employing these strategies, my intention was to help clearly differentiate me from the ward nursing staff. This might have been in part for my own benefit, rather than the benefit of others. The following memo indicates the initial reservations I had in 'entering the field' as a nurse researcher, rather than as a clinical nurse. The memo was added to over a period of time as indicated by the dates of the different entries.

Memo

I have found it difficult to enter the Paediatric Unit to seek out children to interview. There are a multitude of reasons for this and I think some of them include: activity levels are very high, staff always are very busy, and I feel very obvious, inappropriate and intrusive entering the unit 'with clipboard in hand' looking to interview children. I feel I should be helping out with the real work of nursing, not sitting down talking.

This goes to the notions of 'the busy nurse', the value of research in nursing, my role as a member of the paediatric nursing staff and member of the team. It might also be, of course, the fear factor of conducting the interviews!

I speak of the value of research in nursing and this is a concept that I espouse – fostering a culture of research in nursing and of connections between clinical nursing and research

activities. But here I am. How important do I see this research topic? I argue for the need to know how children experience their hospitalisation. Only through identifying their needs will we be able to provide quality care that is truly child centred. Paediatric nursing is an area of nursing I have been practicing in for so much of my career. I love it. I have been a little offended when people have encouraged me, in order to progress in my career, to gain experience in other areas of nursing – as though paediatrics is not real nursing and does not require the same level of skills, competency and knowledge of these other areas of nursing. Paediatric nursing is also 'off the research agenda.' Even in the school, research with children is invisible within the research focus areas, subsumed within the 'women and families' area. Children are once again silenced and marginalised.

However, staff have always been very happy to make the initial approach to parents on my behalf. They appear to be genuinely interested and welcoming and I think it is my own insecurities that prevents me from going in 'full steam ahead'

How can I overcome this? I have found beginning analysis and coding really interesting and inspiring for further data collection. 13.3.06.

Taking long service leave was in order to progress data collection and analysis. It has certainly given me a good incentive. I must use this time to best effect. I would be very cross with myself if I just squandered this time. It also allows me to have a different role. When I visit the ward, I wear my university ID, not the hospital ID. Although I talk to the staff, I don't get involved in 'ward work'. They express real interest in the research and actively support it, through things like identifying possible participants and in helping to identify appropriate quiet spaces to conduct interviews 23.03.07.

When undertaking observation in the perioperative unit, I wore surgical scrubs, similar to those worn by the staff in this area. This meant that for the children and their parents, I could possibly be taken for a member of staff. In all periods of observation I introduced myself to staff, children and parents as a nurse who was undertaking research about the experiences of children who have surgery. During these periods of observation within the perioperative setting, introducing myself and explaining my role was particularly important so that children and parents had a clear understanding of my role.

However, I found that there were times when roles became blurred. On one occasion, in the preoperative waiting area, a mother told me she had just found out that the surgery her child was to have was more extensive than she had previously understood it would be. The child was admitted as a day procedure patient and was to be discharged home following recovery from the surgery. The mother was worried about whether she would be able to manage the level of care her child would need on discharge. It was in the interests of this child and mother for me to act on these concerns. In this instance, I reported the mother's concerns to the admitting nurse so her concerns could be relayed to the surgeon. The surgeon spoke to the mother prior

to the child's surgery about the surgical procedure and outlined the child's care requirements. In doing so, the requirements for informed consent for surgery were fulfilled and the anxieties of the mother were allayed. Perhaps the mother had felt able to disclose her anxieties to me because she saw me as a member of the health care team. I may also have appeared approachable because I had sat with her and her child, and made conversation with them both, and I was not seen to be busy, like all the other staff. The decision to advocate for the child and mother was important and I had both a moral and ethical obligation to do so.

The literature as a source of data

A further source of data for this study was literature and documents relevant to the field of study. The use of literature in grounded theory has been a contested issue. In traditional grounded theory, the literature is initially avoided in order to prevent contamination, stifling or limiting of the researcher's analysis of codes emergent from the data (Glaser and Strauss 1967, p37). However, the literature can also provide examples of similar process and stimulate thinking about properties or dimensions that can be used to examine the data (Strauss and Corbin 1998, p45). Classic grounded theorists advise that the literature review should be delayed until after completing analysis so that data is not viewed through the lens of earlier ideas and the data is not forced into pre-existing categories (Glaser and Strauss 1967, p37). Others argue for researchers to take a more critical stance toward these earlier theories and that extant concepts be required to earn their way into the study being undertaken, and the categories and theorising that result (Charmaz 2006, p166).

In the following sections of this study, relevant literature has been interwoven into the findings. Treating the literature in this way, that is, interweaving the literature throughout the process of evolving a grounded theory, resulted in the literature forming another voice that contributed to the theorising. In addition, the literature was used to help clarify ideas; to make comparisons; to further theoretical discussion and show how and where this work fits or extends relevant literatures (Charmaz 2006, p167). By doing so, this approach to the literature also resulted in a dialogue with current conversations within the discipline of nursing and the specialty of paediatric nursing in particular. This means that the current study is therefore positioned within the current knowledge of these areas of nursing.

The use of Rich Picture diagramming

The information and findings generated from the data are rich and complex and I found it difficult to present them in a linear form. In seeking to present the rich information from the data sources, a technique from Soft Systems Methodology (SSM), that is Rich Picture Diagramming (RPD) was used. SSM was developed by Peter Checkland as a flexible approach to problem solving in the context of complex human problems (Checkland and Scholes 1999). Making drawings to indicate the many elements that are inherent in human situations has been integral to SSM. However, RPD can be a tool used quite separate to SSM (Ho and Sculli 1994, p56). Further, RPD is a tool that has been recognised as being consistent with a grounded theory approach, and can assist with analysis and theorising (Sutrisna and Barrett 2007, p165).

The use of diagramming in grounded theory is a recommended approach that assists with considering the relationships between categories. Diagrams are also central in grounded theory work, creating a visual display that allows distance to enable conceptualisation of the data in more abstract terms. Diagramming therefore represent categories and their linkages more precisely and concisely than text. The diagrams in grounded theory are often messy, partial and provisional (Lempert 2007, p258). Increasing numbers of grounded theorists are using diagramming as an effective way to integrate their ideas and to establish the logic of their ordering (Charmaz 2006, p12).

RPD 'is not a methodology but rather a tool that can be used to support subsequent analysis leading to theory building' (Sutrisna and Barrett 2007, p175). The activity allows a generalisation or abstraction of the findings that can facilitate theorising. They include elements which influence the problem, but that may not be captured by more formal methods of analysis. Rich pictures represent structure, processes and issues that are relevant to the problem definition, and give an impression of the environment.

Rich pictures are artistic and individualistic expressions, and therefore not 'right' or 'wrong'. They act as a vehicle to help users explain the issue of concern to others. They do this through the use of symbols and diagrammatic conventions that represent a particular situation in a manner that is explicit and understandable by

others. Each person develops their own style of rich picture, perhaps starting with people or locations.

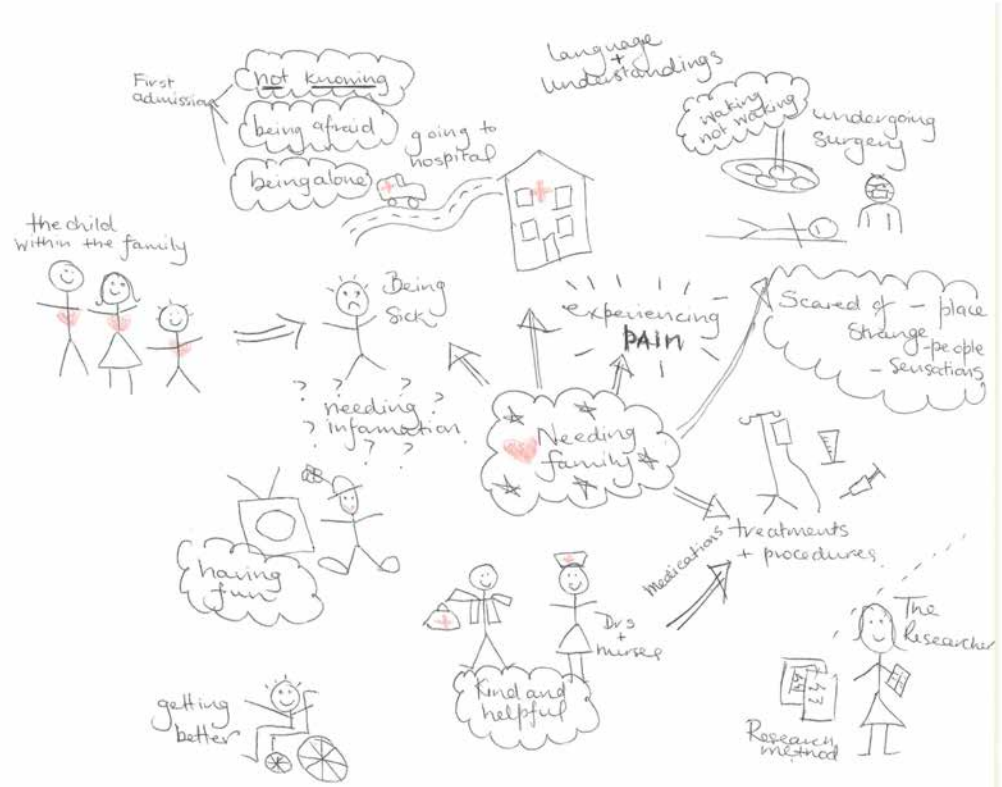


Figure 4: Rich Picture Diagram no.1

The rich pictures developed in this research attempted to capture the issues of concern around children's hospitalisation for surgery identified from the analysis of the data (see Figure 4: RPD 1). The diagrams presented the child as a member of a family – who were seen as the central unit for the child. Throughout their hospitalisation, children relied on their family for care and support. Children who had no previous admissions to surgery, had no prior, or very limited knowledge and understanding of hospitalisation and surgery. Those who had previous experience had, to different degrees, some knowledge and understandings that they could draw on to assist in coping/understanding with their admission. The time around the children's operation presented a critical time for all the children. Receiving treatments and having procedures were a further cause for anxiety for them.

Receiving information was helpful for the children in assisting them to make sense of what was happening to them. The children saw nurses and doctors as kind and helpful and they assisted the children through the experience. The researcher and research method were included in the rich picture in recognition that I am not separate from the research processes.

In addition, the rich pictures were later used to illustrate the processes as described by the children – and so present their perspective (see Figure 5: RPD 2). My theorising of their experience led to the identification of the processes the children were engaged in and these were identified as: ‘coming to know’ and ‘bouncing back’. The context required for these processes to take place for the children was a holding environment, that was termed ‘being held’. Rich pictures helped to illustrate the interconnecting processes that the children were engaged in when they were admitted to hospital for surgery.

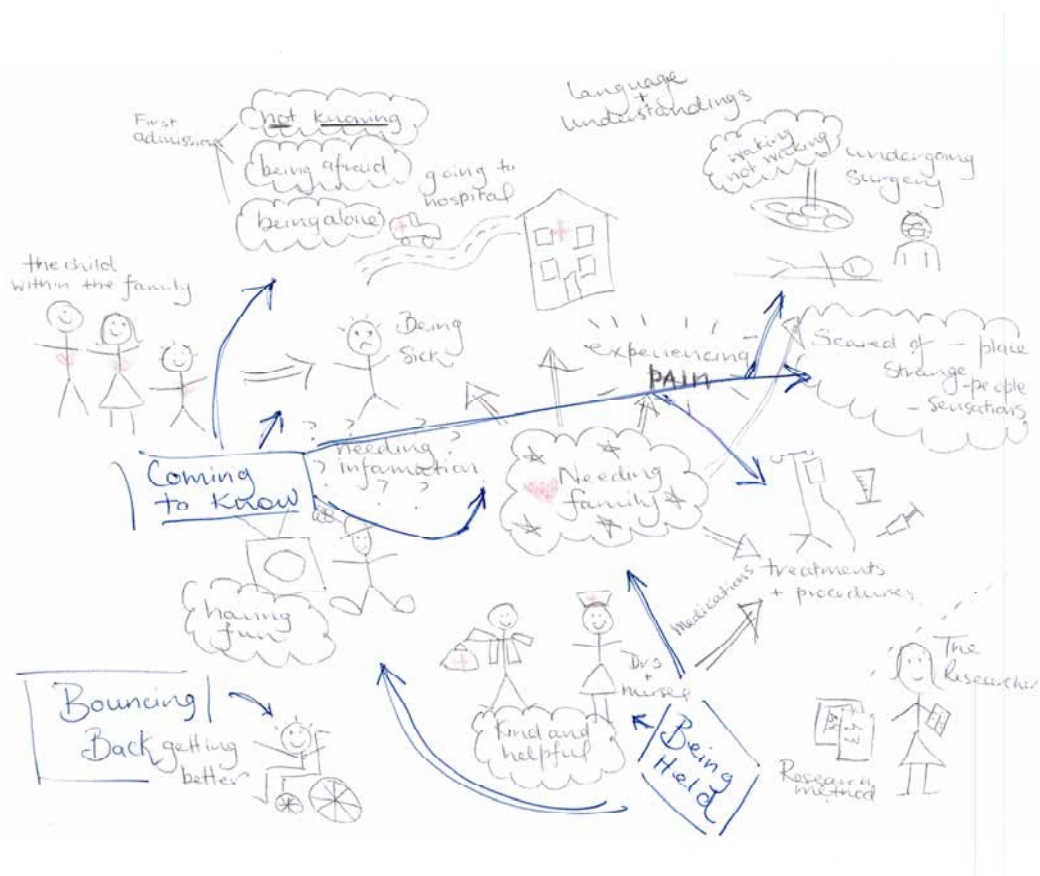


Figure 5: Rich Picture Diagram no.2

Data management

Interviews with children, their drawings and stories and my own field notes and memos, as well as the literature were recognised sources of data in this grounded theory study. All of the different sources of data contributed to the understandings and theorising about the children's admission to hospital for surgery.

Taped interviews were transcribed verbatim by me. There are recommendations within the literature for only transcribing parts of the data that are considered important. I transcribed entire interviews with the children, so that I did not risk losing something that might later be recognised as significant. Although time consuming, by transcribing the tapes myself, I found I was immersed deep within the data and closer to the lived content of the interview, attuned to the contextual meanings of the children's words. This meant that when I later re-read the words, the mispronunciations, inflections or emphases given by the children, remained with me – I heard their voices, and this was a way of coming as close to them (the children) as possible through the data. The process of transcribing also required a degree of sensitivity to the process of transforming oral language to written text representation.

The computer-aided qualitative data management software, N-Vivo (QSR International Pty Ltd 2002) was used to assist with the data management and analysis in the initial stages of the process. I had attended a workshop in the use of this software, and was open to the benefits such tools presented in achieving efficient and effective data analysis and management. The software was used for part of the initial line-by-line coding process (however this was also attended to manually). I found that I kept returning to the manual process more and more for constant comparison, creating linkages and for memo writing and theorising, and that I used the software less and less. The mechanical operations involved in using the software did not compare to the 'nuanced interpretive analysis' described by Charmaz (2000, p520). I found a greater intimacy with the data through the physical handling of the pages of written word, and the reading and re-reading of these pages. Again, through this manual process I found I was closer to my data.

Codes and categories were sorted and resorted, moved and revised and I wrote in a series of workbooks and on sheets of butcher's paper to capture different iterations

and conceptualisations. It was a messy, fluid and iterative process, where some ideas were discarded, and some were later returned to.

The decision to retain a sense of individual children in data entries in this report was given careful consideration. There is a delicate balancing act in enabling the children's accounts to retain a degree of visibility in the text so that the reader is able to make connections with the analytical findings and the data that gave rise to these. However, there was also a potential to reveal individual children's identity through the way data is presented. Making connections clear was a way of demonstrating the value I placed on the children's contribution and also the ethical obligations I had to describe their experiences in the most faithful way possible, whilst still maintaining confidentiality. By keeping the children's words intact in the process of analysis, their presence was maintained throughout (Mills et al. 2006a, p12).

Incorporation of my own questions or comments in the interview excerpts presented in this work serves to give context to the children's own comments. It also recognises the co-creation of meanings that takes place between the participant and researcher in constructivist grounded theory.

This section has provided an account of how the different data sources were utilised in the study. The account has included some of the practical challenges inherent when conducting research with children and how these were addressed in the study. By doing so, the unique situations, practical sticking points and dilemmas involved in this research project with children are made transparent. Not all of the methods were found to be suitable for all the child participants. The needs of each individual child needed to be considered in order for their contribution to be achieved in a way that was respectful of their own choices and abilities.

Data analysis

This section details the research methods used in analysis of the data. Grounded theory is not a linear process. Rather, the approach is concurrent, iterative and integrative as data collection, analysis and conceptual theorising occur simultaneously and from the beginning of the research process. This process continues throughout until the theory is developed. In the current study, through data collection and analysis, theoretical possibilities within the data emerged. Some of

this process is difficult to document in a form that fully captures its complexity and the abstract nature of parts of the work. This section on analysis of the data provides a written account of this part of the research journey.

Data, according to Charmaz (2000), are narrative reconstructions of experience, they are not the original experience itself (p514). The different sources of data used were interviews with children; their drawing and associated writings; my own observations documented in memos; and as is consistent with grounded theory, relevant literature, including reports, records and reflections. Analysis of the data began with coding.

Coding of data was undertaken according to the processes described by Charmaz (2006). The process of coding had two phases – initial and focused coding. Although Charmaz does not provide a detailed explanation of the steps between the major phases of coding and analysis (Chen and Boore 2009, p7), the following sections outline the processes that were used in the research. Developing concepts and theoretical frameworks had several phases:

1. Creating and refining the research and data collection questions;
2. Data collection and initial coding;
3. Initial memos raising codes to tentative categories;
4. Further data collection and focused coding;
5. Advanced memos refining conceptual categories – adopting certain categories as theoretical concepts;
6. Sorting memos;
7. Integrating memos and diagramming concepts; and
8. Writing the first draft.

Figure 6 presents the analytic process used in the study, based on Charmaz (2006, p11).

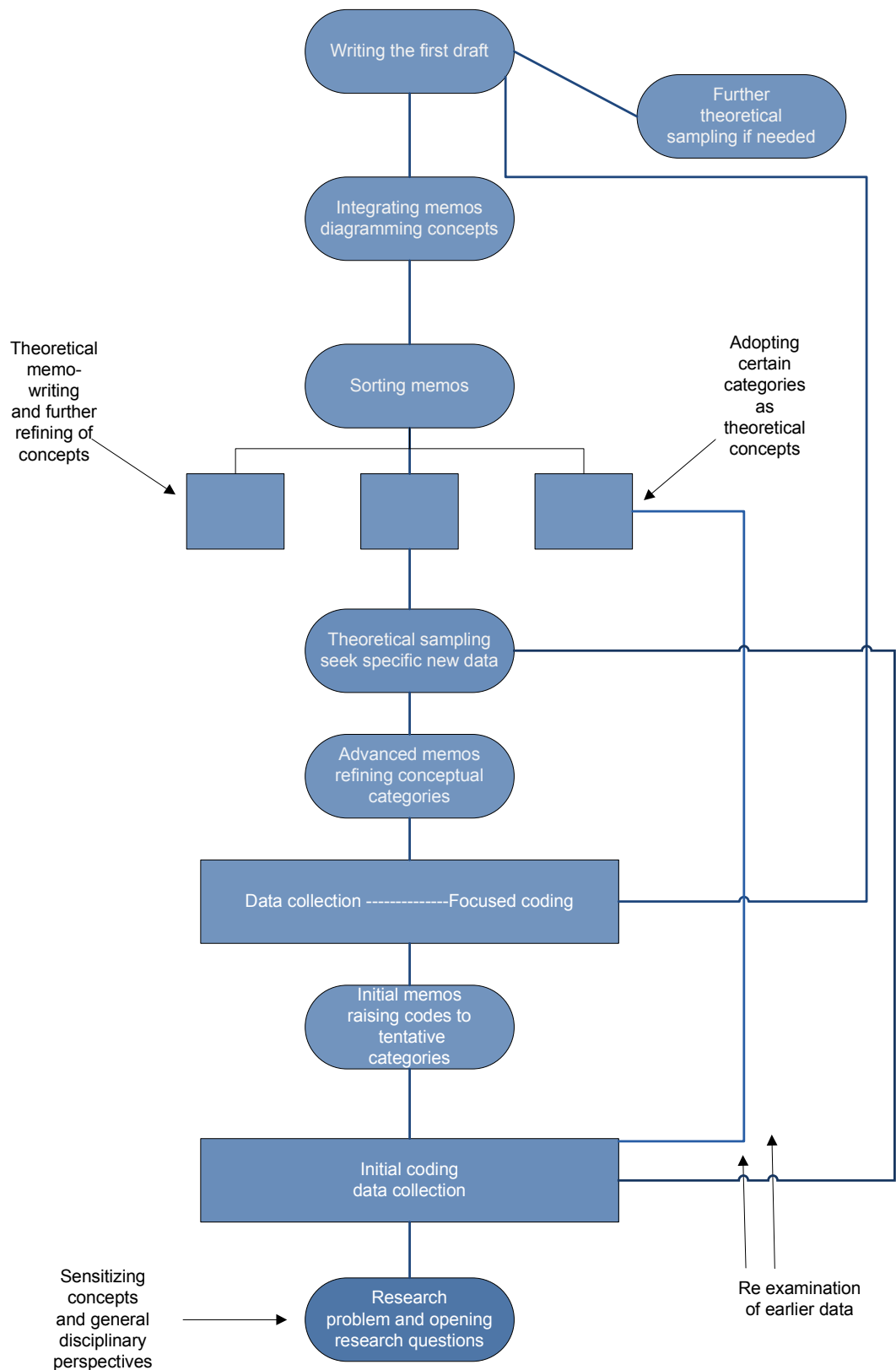


Figure 6: The analytic process based on Charmaz (2006, p11)

Initial coding

Coding of the emerging data was undertaken as it was collected, and this allowed me to start to define and categorise the data. An early course of action in studying the emerging data involved line-by-line coding. This form of coding required examining each of the transcripts from the participant interviews, as well as their stories, line-by-line. This form of coding prompted close study of the data – line-by-line – and the beginning conceptualisation of ideas (Charmaz 2006, p11) (Appendix 5 is an example of line-by-line coding of an excerpt from one interview). The initial coding assisted in analysis of the data from the ground up, based on the participants actions and statements, and reduced the likelihood of superimposing my own preconceived notions on the data (Charmaz 2006, p51).

Often the children's own words (in vivo coding) or gerunds (words ending in *ing* that reflect process rather than topic) were used as codes. This was in order to convey a sense of action and imagery as well as to stay close to the data, and therefore the meanings the children were conveying. Starting with the words and actions of the children helped to preserve the fluidity and provided a way of looking at their experience, from their perspective. Appendix 6 is an example of texts across interviews for the code 'being scared'.

If the participant's meanings and actions are glossed over, the grounded theory is more likely to reflect an outsider's view, rather than an insider's view. In addition, there is a risk of importing an alien professional language to describe the phenomenon (Charmaz 2006, p49). The codes used in the analysis of the data were close to the data, as they came from the data and they give an indication of the children's own perspective, using the language of the children. Further, it was also evident that in vivo codes from within the data provided symbolic markers of the children's own language and meanings.

One example of this form of coding, that is both in vivo coding and a gerund is provided. When asked what he thought when first told he would need an operation, one boy said he didn't really like the idea, *but it sounded exciting* (Boy, 6yrs). *It sounded exciting* was an initial in vivo code that was used to indicate one of the positive feelings children described around their hospitalisation and surgery, expressed as a gerund. *Being left alone* was another in vivo code from early analysis

that is also in the form of a gerund. This code describes the fear children expressed that being in hospital would mean that they were left alone, and that they would be away from their parents. *Hurting* was another initial code and expressing this concept as a gerund preserves the sense of action that is a part of the children's experience of pain. Replacing the gerund 'hurting' with a noun like 'hurt' or 'pain' for this code risked reducing this important notion to a mere topic, and therefore losing the sense of action and process inherent within it (Charmaz 2006, p49).

Focused coding

Focused coding was the next major step in the coding process, and focused coding is more directed, selective and conceptual than the initial coding process. Focused coding was used to synthesise and explain larger segments of data and required using the most significant or frequent earlier codes to sift through this data (Charmaz 2006, p57). When undertaking focused coding, I moved across interviews, drawings, stories and observations and compared the children's experiences, actions and their interpretations of what was happening. So in relation to the code 'hurting' for example, I looked at all the sources of data to see how each child talked about pain. I compared what each said about the experience and this helped me to refine the code of 'hurting'. I was led to look at the causes of their hurting; the effect of their hurting; the ways the children actively responded to experiencing pain; the strategies they used; and the supportive strategies they drew on. I went on to develop the initial code 'hurting' as a category.

A category is a theme or variable that aims to make sense of what the participant has said. It is interpreted in the light of the situation, and other interviews, and the emerging theory. Categories explicate ideas, events, or processes in the data (Charmaz 2006, p91). The early categories were considered provisional because, in keeping with the grounded theory method, it was important to remain open to further analytic possibilities. Ongoing comparative analysis and conceptualisation resulted in some changes in the initial coding. So that an early code 'being in hospital' was further developed to 'sense of place' part of the category 'locating their selves'. This was in recognition that part of the process of making sense of the experience of hospitalisation for surgery required the children to make sense of the place they were in.

Constant comparative analysis

Grounded theory utilises constant comparative analysis to establish analytic distinctions and to determine if the data supports and continues to support the categories that are emerging (Holton 2007, p277). The constant comparison method required that I continually return to the data, and the words of the children, using previous data and analysis to influence future collection and analysis. The process of constant comparison involved comparing incidents to other incidents to establish uniformities and varying conditions that could be identified. It also involved comparing emerging concepts to more incidents for the purpose of 'theoretical elaboration, saturation and densification of concepts' as well as the comparison of emergent concepts with each other (Holton 2007, p278). Associated with this process was memo writing, and I wrote a number of memos about my interpretations and analysis throughout the process (Memo writing is discussed in more detail below).

Analysis of the data showed that children often talked about their need for their parents to be with them throughout their hospital stay. One child said one of the most important things for her in hospital was that

Mum and dad had to stay with me, that one of them had to stay with me (Girl, 8yrs).

Whilst this was a common idea expressed by a number of the children, analysis and comparison of the data revealed another view that was expressed by other children. The parents of some children did not spend all day and all night in hospital with them, but one of their parents was noted to be present at crucial times of the children's admission, such as their induction of anaesthetic. According to all of the children, it was most important for a parent to be with them at such times. So the need for parents to be in constant attendance turned out to be one view of the children. Another view was that the children's parents needed to be present at crucial periods during the hospitalisation.

The coding process made me think about the data in new ways. Some of my own taken for granted, hidden assumptions were challenged, and I was made to look at what was (seemingly) familiar in a new light. One example of this was the children's

acceptance of the need for their surgery to make them better. When I asked in an early interview how the child felt when he woke from his anaesthetic he told me he felt *better* (Boy, 6yrs). When I clarified (for myself) what he meant by this, he meant that his surgery for acute appendicitis made him feel better. What I was expecting to hear was something quite different, perhaps that he was in pain or felt unwell on waking. These things were indeed described by this child, as well as by others, but the notion of the surgery making the children better was something I had not expected to hear from them. This notion came to be recognised as an aspect of the children's resilience and coping strategies in the theorising of the data.

Memo writing

Through memo writing, my thoughts about what I was seeing in the data, the similarities and the differences were captured and explored. Memo writing is a pivotal step in grounded theory between data collection and writing drafts and is where researchers stop and analyse their ideas about their codes and emerging categories. Potential categories are established, and the codes they subsume are identified through the activity. I found that the sorting of memos helped in the generation of the theoretical outline or conceptual framework for the work. The process assisted in looking for similarities and connections within the data, where to locate codes and categories, and in the resultant theoretical higher order conceptualisations. Ideas and insights were developed and, as Charmaz (2006) states, memo writing forced me to stop and engage different categories – my memos formed a place for exploration and discovery around the ideas I had about what I had 'seen, sensed, heard and coded' (p82).

Achieving saturation or theoretical sufficiency

The notion of saturation in grounded theory is that data collection stops when saturation occurs: Saturation has been defined as 'data adequacy' that involves collection of data until no new information is obtained (Morse 1995, p147). Charmaz (2006) states that saturation is when new data no longer trigger new theoretical insights, and new properties of core theoretical categories are no longer revealed (p113).

However, saturation does not simply mean the repetition of the same events or stories. The frequency of reportings in the data is not of major importance. Important

to the process of analysis of data, however, is that all data is given equal attention: 'eliciting all forms or types of occurrences, valuing variation over quantity' (Morse 1995, p147). Richness of data comes from detailed description and does not depend on the frequency something is stated. It may, in fact, be the infrequently occurring 'gem' that provides perspective and becomes a central key to understanding and development of a theory explaining the phenomenon. There are few guidelines or tests of adequacy for determining the sample size or the amount of data required to achieve saturation (Morse 1995, p147). And according to Charmaz (2006), the notion of saturation of categories supersedes that of sample size, and sample sizes for some studies may be quite small, yet still achieve the requirements for a project (p114). A grounded theory study needs to be representative, but researchers are advised that it is unnecessary and even defeating to collect huge amounts of data. The risk is that large files go unanalysed, or the researcher becomes overwhelmed by the sheer volume of data and loses sight of the fundamental processes within the area of study (Stern 2007, p117).

The notion of saturation and whether saturation is at all achievable has been challenged and the term 'theoretical sufficiency' has been used instead to indicate the adequacy of data and fullness of coding (Dey 2007, 2003, Charmaz 2006, p114). The reasons for this position are that categories are in reality produced through partial rather than exhaustive coding, and because coding is not achieved for all data. It is argued that the term 'saturation' is imprecise in grounded theory studies and that categories are *suggested* by the data, rather than saturated by the data. Saturation may in effect be an artefact of the way researchers focus and manage data collection, and the resulting legitimacy of claims about saturation can be questioned (Charmaz 2006, p114).

Data collection for the study continued until no new theoretical insights were achieved. In recognition of the concerns about the notion of saturation, the adequacy of this sample size and associated data will be determined by the thoroughness of the data as well as the rigour of the analysis. The aim of this study is to achieve the theoretical sufficiency Dey and Charmaz call for.

Theoretical sampling

Theoretical sampling is all about the concepts and categories you are developing and the testing you do of them (Charmaz in Puddephatt 2006, p15).

Theoretical sampling means seeking and collecting data that elaborates and refines categories in an emerging grounded theory. 'Theoretical sampling involves starting with data, and then examining these ideas through further empirical enquiry' (Charmaz 2006, p102). When questions arise from the data and when gaps are identified, the researcher seeks to answer the questions and close the gaps. This can be achieved through returning to individual research participants, or by seeking this information from other research participants. This process of theoretical sampling achieves increased understanding and strengthens the analytic categories.

Theoretical sampling differs from initial sampling and purposeful sampling. In initial sampling, criteria for people, cases or situations are established prior to entering the field - it is where the researcher begins. Purposeful sampling seeks a representative sample based on, for example, quotas or demographics. However, theoretical sampling relates to conceptual and theoretical development – it directs the researcher where to go, based on the theoretical analysis (Charmaz 2006, p96). Theoretical sampling is where statements, events or cases are sought to illuminate categories so as to fill the properties of the categories, as well as to assist in determining how processes develop and change.

In this study, theoretical sampling was undertaken, but as has been found in other grounded theory studies with children (Coyné 2005), this part of the process was not straight forward. Careful consideration was required to determine how this crucial component of a grounded theory study was to be achieved. The research plan included the provision for interviewing individual children on more than one occasion. Initially, the main reason for this was to enable me to follow the children's experiences of hospitalisation and surgery over time. However, the ability to conduct follow-up interviews with key 'informants' (Charmaz 2006, p111) also provided the important opportunity to follow-up major ideas and thus allow for theoretical sampling. The provision for possible subsequent interviews and observations to allow for theoretical sampling and address conceptual issues is a strategy identified by Charmaz (2006, p111). Theoretical sampling was used in order to refine

categories that were emerging, and to develop their properties. For example, early on in the data analysis, I identified a category that related to the children's interactions with nurses. In analysis of the first interview, the child referred to his interactions with nurses on different occasions. In a couple of instances, he talked about them in a rather remote fashion, and he mistook the hospital clowns as nurses dressed up. I wondered what his interactions with nurses meant for him as well as for other children. Theoretical memos helped me to explore and refine this idea. Theoretical sampling required me to check my ideas against direct empirical realities, moving back and forth between the category and the data (Charmaz 2006, p110). In my subsequent interviews with children, including the follow-up interview with this child, I questioned directly around this aspect of the children's experience.

Theoretical sorting

Sorting, diagramming (through the use of Rich Picture Diagrams – described previously) and integration of memos were inter-related processes that were required strategies in the theoretical development of the analysis. The sorting of analytic memos served the emerging theory and provided the means for creating and refining theoretical links. Sorting assisted in the theoretical integration of categories and prompted the comparison of categories at an abstract level (Charmaz 2006, p115). The sorting, comparing and integration of memos was complicated by the fact that more than one process was identified and several categories were present - so the process was not 'clear-cut' (Charmaz 2006, p117). I was required to try several different sortings and the suggested process by Charmaz (2006) assisted this work:

- Sort memos by the title of each category
- Compare categories
- Use the categories carefully
- Consider how their order reflects the studied experience
- Think how their order fits the logic of the categories
- Create the best possible balance between the studied experience, the categories and the theoretical statements about them (p117).

The practical activity included experimenting with several different arrangements of memos using cards with the title of the different categories and using the Rich Pictures to visualise relationships between different concepts and categories.

Because there were several categories, the process of sorting and diagramming needed to demonstrate how the different categories fit together.

The ambiguity of negative cases

The logic of negative cases assumes asking whether data do not fit the analysis, and that their source and how they are used shapes their fit with grounded theory (Charmaz 2006, p102). Negative cases may, according to Charmaz (2006), compliment or contradict grounded theory (p101). Clarke (2005) refers to negative cases in grounded theory as one of the positivist 'recalcitrances' of traditional grounded theory, and prefers instead to refer to the 'range of variation' in data (p16).

In this study, the negative cases arose *from* the data and were not imported into the research process as though to further theoretical sampling and as the negative cases emerged, I was required to refine the emerging theory (Charmaz 2006, p102). Exploration of the 'negative' or atypical cases that emerged from the data challenged the adequacy of the insights and the formulation of more dependable and credible conclusions. Rather than discounting those findings, the negative cases were analysed to give strength and rigour to the development of the emerging theory.

Examples that emerged included: 1) Children who had previous admissions to hospital had some different perspectives to those of children admitted to hospital for the first time. Analysis of their experiences led me to identify the importance children's previous experiences had in their processes of meaning making, assimilation and accommodation. 2) Most children talked about liking the hospital food and talked about special food treats. But one child did not like the food, and described unusual and unfamiliar food choices. This led me to identify that it was the familiar nature of the food, and more broadly, other aspects of hospital, that the children found to be of importance to them. In being able to make links with the familiar things in their lives they were better able to situate themselves within the unfamiliar setting of hospital. 3) One child wrote about the worst parts of her stay that comprised a criticism of her experience, including care from nurses. The child indicated non-caring responses by nurses was hurtful and distancing. For instance, other children talked of the nurses call bell and expressed trust that the nurse would always respond. This child wrote about how this was not the case and of how the nurse did not respond. This indicated to me how important the nurses' role was to the

children and that the children's trust in the nurses could be breached – even without the nurse being aware of this. Consideration of the child's experience indicated that when children did not feel supported and cared for – that is when they did not experience 'being held' - their experience was not positive. In this instance, the negative case strengthened the finding that provision of a facilitating holding environment, afforded by both parents *and* nurses was an important part of children's experience.

Conceptualisation

A conceptual framework links concepts and serves as an impetus for the formulation of a theory (Bowen 2006, p3).

In the Meadian sense, the questions are: Who and what are in this situation? Who and what matters in this situation? What elements 'make a difference' in this situation? (Clarke 2005, p87).

In order to achieve theorising, researchers must seek to move beyond the coding stage of analysis to raising main categories to concepts (Charmaz 2006, p138). It is the most significant categories that become concepts of the theory (Charmaz 2006, p186). Determining which categories were raised to theoretical concepts required identification of categories that rendered the data most effectively and that carried 'substantial analytic weight' (Charmaz 2006, p139). It is these categories that were seen to have theoretical reach, incisiveness and power and related to other categories.

From the initial coding categories, core conceptual categories were identified (Charmaz 2006, p47). Categories can be both major and minor and after a time categories were found to emerge with both high frequency of mention, and to be connected to many of the other categories that were emerging and these were identified as the major categories. I acknowledged a potential danger of choosing major categories too early in the data collection, but over time it became clear through the analytical process that specific categories were well connected to other categories. The following quote from Charmaz (2006) discusses the elevation of categories to concepts, and identifies that in traditional grounded theory, concepts serve as core variables. However, the core variable is not a feature of constructivist grounded theory, where concepts serve as interpretive frames:

Raising categories to concepts includes subjecting them to further analytic refinement and involves showing their relationships to other concepts. For objectivists, these concepts serve as core variables and hold explanatory and predictive power. For constructivists, theoretical concepts serve as interpretive frames and offer abstract understanding of relationships. Theoretical concepts subsume lesser categories... hold more significance, account for more data and often are more evident (pp139-140).

Concept development in this study led to theory development. Theory is distinct from description (Corbin and Strauss 2008, p53) – description is the words of the person that invokes mental pictures of objects, events and experiences, whilst theory is abstract and explanatory (Charmaz 2006, p133, Corbin and Strauss 2008, p54). A number of works claiming to be grounded theory studies have been criticised for being purely descriptive. There is a risk in grounded theory studies that a disjuncture can arise between the analytic level and theorising and this can lead to a descriptive study that does not include theorising. According to Holton (2007)⁵:

While tied to experience, conceptual abstraction directs attention to and isolates a part or aspect of an entity or phenomenon for the purpose of contemplation... While the descriptive findings of a qualitative research study are most certainly valuable, they do not provide a conceptual abstraction. A grounded theory must offer a conceptually abstract explanation for a latent pattern of behaviours (an issue or concern) in the social setting under study. It must explain, not merely describe what is happening in a social setting (p272).

Theoretical concepts were developed through the repeated processes of moving back and forth between the data, that itself was becoming increasingly more focused and the categorisations of the data were becoming increasingly more abstract. The theoretical concepts that were developed in the current study were ‘being scared’; ‘hurting’; ‘having fun’; ‘coming to know’; ‘bouncing back’ and ‘being held’. The concepts ‘being scared’; ‘hurting’; ‘having fun’ were found to represent the phenomenon of the children’s experience. ‘Coming to know’ and ‘bouncing back’ represented the processes they were engaged in and ‘being held’ represented the context.

⁵ The quote from Holton regarding the intent of grounded theory studies refers to *explanation*, but constructivist grounded theory refers instead to *understanding*.

Questions of the analysis:

The purpose of the study was to explore the experiences of primary school age children who are admitted to hospital for surgery, from their perspective. The following questions assisted in the analytical processes:

- How do children come to this experience?
- How do children's understandings of hospitalisation and surgery develop?
- What are the important influences on this process?
- How did children engage in the making of meanings?
- What were their understanding of the main concepts, ideas and experiences?
- What sort of knowledge did the children have - before, during, and after their hospitalisations and
- What mechanisms accounted for this knowledge?

These questions helped in the development of the theory that emerged from the processes of analysis and conceptualisation.

A single Basic Social Process?

I have learned there can be more than one social process... There may be many processes that are operating within a setting (Charmaz in Puddephatt 2006).

Earlier grounded theory works (Glaser and Strauss 1967, Glaser 1978) stressed the need for identification of *the* basic social process that the researcher discovers as fundamental to grounded theory research. Basic social processes shape participants actions and understandings within the setting (Charmaz 2006, p20). Process in this instance means change over time 'in patterns of action/interaction and in relationship with changes in conditions' (Wiener 2007, p306). However, Charmaz (2006) writes that the discovery of a single process that unifies everything that is learned may not be able to be identified, as numerous 'basic' processes can occur in a setting. When this is the case, determining the most fundamental process can be difficult (p139). Other constructivist grounded theorists also critique the notion of a *single* basic social process (Clarke and Friese 2007, p369, Clarke 2005, p16). In this work, identifying a single basic social process was not able to be determined as a number of processes were identified that captured what I had learned about children's admission

for surgery, from their perspective. Eventually, the social processes identified that best captured the processes the children were engaged in were ‘coming to know’ and ‘bouncing back’.

‘Coming to know’ presented the change in the children’s knowledge and understandings that occurred over time and with experience. These changes were seen from prior to the children’s admission to hospital, over the course of admission and following their discharge from hospital to home. The second process, ‘bouncing back’ refers to the resilience of the children and their ability to accommodate and assimilate the experience of hospitalisation and surgery into their self, and to move on with their normal life following this experience.

Theorising

‘Our work culminates in a ‘grounded theory’ or an abstract theoretical understanding of the studied experience’ (Charmaz 2006, p4).

... the most we can do is theorize... To me, theorizing is a tool for generating working understandings and need to be regularly revised, updated, tossed out and reinvented in the face of changes... theorizing offers working understandings of particular situations. It is an activity we do and keep on doing---temporary and partial (Clarke, May 25 2005).

Theorising is the professed purpose of grounded theory research and in interpretive works, theorising emphasises understanding rather than explanation. According to Charmaz (2009), the constructivist approach challenges the assumptions of creating general abstract theories and leads us to ‘situated knowledges’ (p136). This research has resulted in my own theorising of the studied experience, that is children’s admission to hospital and surgery from the children’s perspective of that experience and resulted in a substantive theory of the children’s experience.

Theorising means ‘stopping, pondering and rethinking anew. We stop the flow of studied experience and take it apart...when you theorise, you reach down to fundamentals, up to abstractions, and probe into experience’ (Charmaz 2006, p135). Theorising in this grounded theory involved developing abstract concepts and specifying the relations between them (Bryant and Charmaz 2007b, p126). It required the practical activity of ‘engaging the world and of constructing abstract understandings about and within it’ (Charmaz 2006, p128). This kind of interpretive theory is well matched with symbolic interactionism, where actions are the starting

place for analysis ‘that includes the persons’ imagined understanding of the other person’s role and response during interaction’ (Charmaz 2006, p127). How these concepts were arrived at is a very important part of the theorising specifically, and of grounded theory more generally (Bryant and Charmaz 2007b, p25). The theorising process was not transparent nor was it a mechanical process (Charmaz 2006, p135). It involved being open to the unexpected, and even as advised by Charmaz (2006), degrees of playfulness and wonder (p136).

One issue that I was questioned about and needed to reflect on during the course of this research was the perceived difficulty of being able to make abstractions and theory from the ‘childlike’ data that is the stories of the children. However, as argued here, it is the role of the researcher to make these abstractions and undertake the theorising. The words of the children are lacking in the abstract, but they hold a richness and much of value for study. The problem of course has been that to date, the views of children have not been sought, because they have traditionally been seen as being unreliable, incompetent and less valuable than those of adults. There has also been a questioning of the reliability of the data that is obtained from children and the depth and quality of that data, as well as a questioning of the ability to be able to answer research questions based on that data alone.

According to Locke (2007, p575), ambiguity and uncertainty are part of the process of theorising. Locke calls for us to theorise our data – to ask the grounded theory question ‘what is going on here?’ We are aware of the individual words on the page, but through engagement and interaction with the data we need to move through these to the situation they point to.

So in this study, it is about my engaging with children who were admitted to hospital for surgery: talking with them; listening to and reading their stories; through their drawings; their actions; and through observing them as they were engaged in this process. It is from these interactions gained from entering their empirical world to the extent that I could, that abstract understandings about and within it were constructed. By interacting with the data, and analysing it, in studying how and why the child participants constructed meanings and actions, theorising about it resulted.

Substantive theory in grounded theory refers to a set of explanations that account for phenomena within a specific or substantive area. A substantive theory differs from formal theory that provides an explanation of a set of phenomena that have broad applicability across several areas of study. Glaser and Strauss (1971, p177) defined substantive theory as theory developed for a substantive or empirical area of sociological inquiry, such as patient care, for example. They defined formal theory as ‘theory developed for a formal or conceptual area of sociological area such as status passage, stigma or deviant behaviour etc’ (1967, p177). Most grounded theories are substantive theories. They may be an end to themselves, or they may be further developed into a formal theory through higher levels of abstraction and conceptual integration in a wider range of contexts and groups (Lempert 2007, p247).

In this study, the theory developed is a substantive theory, in that the understandings have been derived from research with a group of children who experienced the phenomenon of admission to hospital for surgery. The theory is context specific and is concerned with the process from the perspective of children participating in the research.

Fundamental to grounded theory research is that the theory developed comes from the data itself rather than being forced to fit an existing theory or theories. At the same time, however it is important to place the work and its theorising within the work of other theories and to show how the work goes beyond, or adds to what is already known (Stern 2007, p114). The conceptual development of this work, for instance, has congruity with some areas of children’s cognitive development. For example, Piaget’s (1952) concepts of adaptation, assimilation and accommodation were drawn upon in the conceptualisation of findings and analysis. For a number of the children, their hospitalisation and surgery was an entirely new experience whilst others were able to draw upon their previous experience of admission for surgery. The children were engaged in a process of incorporating their new experiences and understandings of illness, admission to hospital and surgery into their previously familiar and known schemes.

One example from the data of this is illustrated by the comments of one child who had a first admission to hospital for an appendicectomy. The child was initially

frightened and did not know what to expect because this situation was outside of her known and familiar world of experience:

Because it was my first time I had my appendix out (Girl, 8yrs).

However, following her admission and when asked if she would be as frightened if she had to be admitted to hospital in the future, she said:

C: No.

I: Why not?

C: Because I would know how it feels (Girl, 8yrs).

The child had accommodated the new experience into her schemes and had reorganised them to incorporate this new knowledge. This is not to say that any subsequent admission for surgery will be the same, or that the child will not experience anxiety around any possible subsequent hospitalisations (for the findings show that this is not the case). What it does indicate, however, is that the child would be able to draw upon the schemes she now had to provide knowledge that she did not (previously) have.

Conclusion

The research methods used in this study were appropriate for the research aim. The use of age appropriate methods facilitated the children's participation and increased their sense of control in the research process. Interviews with children required consideration of the individual child's development, language skills, cognitive abilities and experience. The forms of questioning used in interviews, including the use of prompts, direct questioning and scaffolding assisted in eliciting the children's meanings. Children's drawings and stories are an example of a child centred technique that furthered understandings, but its use was not unproblematic. My own observations provided another source of data that described the children's actions observed. In describing the ways that practical challenges encountered when conducting research with children were addressed, the work contributes to the discourse about such challenges.

Constructivist grounded theory provided the framework used to guide the analysis process. The iterative process was complex and abstract in nature. In providing an

account of the steps taken in the research process, the chapter supports the validity of the findings by demonstrating the rigour of the research activity.

The next two chapters present the findings of the research and the theoretical insights that resulted.

Chapter 6: Children's admission for surgery - the phenomenon as experienced by children

They looked at my throat and they looked at my ears. They looked at my heart but they didn't look at me (Jolly 1976, p1532).

Constructivists develop our analyses...we offer an interpretation contingent on our knowledge of our participants and their situations. Constructivists view data as constructed rather than discovered, and we see our analyses as interpretive renderings not as objective reports or the only viewpoint on the topic (Charmaz 2009, p131).

The work children were engaged in as they made sense of the experience of admission to hospital for surgery is revealed in this grounded theory study. Grounded theory has been described as an excellent tool for understanding invisible things, as it can be used to reveal the invisible work involved in many kinds of tasks (Star 2007, p79). In this study, the work undertaken by children to make sense of their experience is that 'invisible thing', as such work of children has largely been unrecognised in research and in healthcare.

The next sections of the thesis present results of the analysis and theoretical conceptualisation of the children's admission to hospital and surgery. The findings from analysis and conceptualisations of the data are presented in three parts. This current chapter presents the phenomenon of children's admission to hospital for surgery, encompassed within the major categories, which were elevated to concepts (Charmaz 2006, p139), and that were identified from analysis of the data.

As part of the presentation of findings, excerpts from interviews, stories, my own observations and the literature are provided. The findings of the study are clearly grounded in the data and in this part of the work, the children's words are privileged, while recognising that all forms of data sources were important. So the children's perspectives are presented before referring to the extant literature and my own interpretations.

In describing the phenomenon as experienced by the children, expressed through their own words, drawings and ways, understandings of what it is like for a child to be admitted to hospital for surgery are increased. The concepts of 'being scared', 'hurting' and 'having fun' were developed from the analytical process and were

found to constitute the phenomenon of admission for surgery from the children's perspective. These concepts constitute part of the framework of the theorising that resulted.

Chapter 7 presents the processes the children were engaged in, identified as 'coming to know' and 'bouncing back'. These were the processes that the children were engaged in as they incorporated the experience of hospitalisation and surgery into their sense of selves.

Chapter 7 also presents the context or the conditions that were required in order for the children to successfully incorporate the experience into their sense of self and move on. This context was a facilitating, holding environment, described in this work as 'being held'. The concepts of 'coming to know'; 'bouncing back' and 'being held' are also part of the framework for theorising.

The concepts and categories identified in the study relate to the phenomenon; the processes; and the context; and are outlined in the following model (Figure 7). Presentation in this form assists the reader to see how the pieces fit to create a sense of the whole.

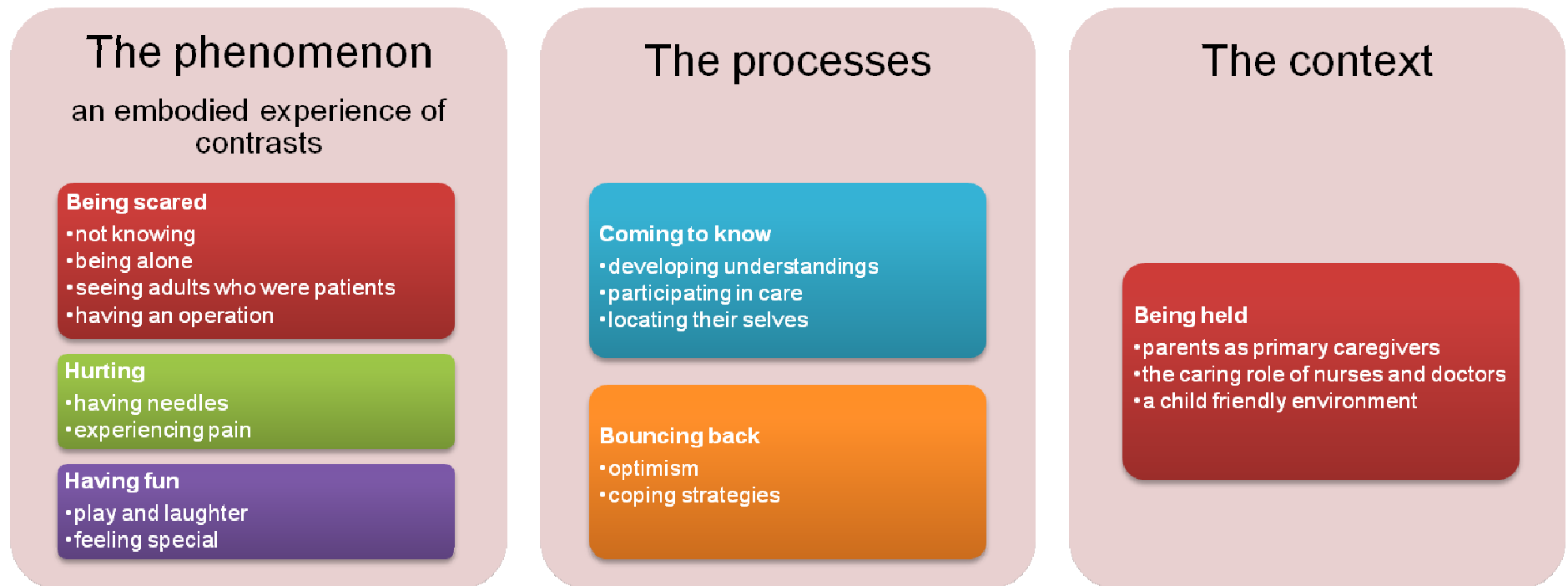


Figure 7: Representation of the phenomenon; the processes and the context

The discussion that now follows relates to the studied phenomenon of admission to hospital and surgery as experienced by the children participating in the research.

The phenomenon - an embodied experience of contrasts

This section presents my account of the children's constructed meanings and actions in their situation. This is from a position that is as close to the inside of the experience as possible, while still realising that it is not possible to fully replicate the experience of the children (Charmaz 2006, p 130).

The children who participated in the study talked to me about what happened to them during the time around their admission for surgery, how they felt about those events and how they made sense of them. They were actively and fully involved in their situation - physically, emotionally and psychosocially. The phenomenon was therefore seen to be an embodied experience for the children. Embodiment in this work recognises the integration of the mind-body-world relationships (Benner 2000, p5). This means that the children's embodied experience of admission to hospital and surgery, that is, their physical, emotional and psychosocial experiences were interactive and essentially linked. Knowing occurred for the children as they were active participants embedded within the phenomenon.

Their experience was also one of contrasts, that once again had physical, emotional and psychosocial aspects. The children's experience of admission to hospital and surgery incorporated the contrasting concepts of 'being sacred'; 'hurting'; and 'having fun'.

The phenomenon is described, therefore, as 'an embodied experience of contrasts' that refers to the wide range of physical, emotional and psychosocial aspects that constituted their experience of hospitalisation and surgery. The contrasting feelings of fear and anxiety and of having fun; and of experiencing pain and recovery; were described by the children. In the following quotes, the children talk about their mix of feelings, of being both scared and excited, and of experiencing pain as well as getting better.

I didn't really like it but it sounded exciting (Boy, 6yrs).

I was happy and scared (Girl, 8yrs).

It was cool and freaky at the same time (Girl, 8yrs).

Sore.. it felt really really sore (Girl, 9yrs).

[Feeling] better (Boy, 6 years).

The contrasting feelings of being happy and scared, of not liking it but of still being excited; of it being '*cool and freaky*' at the same time; and of pain and recovery (feeling better) reflect the complex experience that was their hospitalisation for surgery. These contrasts were found to be evident within the same child as well as between children. This dichotomy presented the children with a situation where, what would normally be considered as contradictory experiences and emotions, existed for them at the same time. I reflected on whether the notion of contrasting emotions experienced as part of the phenomenon caused the children increased inner confusion and distress. I found, however, that the positive emotions and experiences served to ease some of the negative aspects of their experience and indeed constituted an important coping strategy for the children (this is explored in detail later in the findings). The major categories, elevated to concepts that reflect the children's experience, were 'being scared'; 'hurting' and 'having fun'.

The contrasting feelings of children who experience illness or hospitalisation have previously been identified in hospitalised children. Forsner, Jansson and Sorlie (2005) explored children's lived experience of illness and found that the children participating in their study described illness as an experience of contrasts, of feeling scared and confident; sad and cosy; hurt but having a lot of fun. The researchers also described these contrasts in the experiences both within the same child and between children. Research by Carney et al (2003) found that hospitalisation for children involves a range of emotions that included anxiety, relief, happiness and worry.

The children in this study described their admission and surgery as an experience of contrasts that involved the children's whole being. Their experience incorporated physical, emotional and psychosocial aspects of the child's embodied self. The effects that admission and surgery had for the children are discussed in the following sections.

Being scared

‘Being’ describes how the children experienced the phenomenon under study and ‘scared’ describes a negative reaction of the children to their hospitalisation and surgery, ranging from feelings of unease to those of fear.

Although they described a range of feelings, fear and anxiety were found to be overarching emotions for the participating children, and these feelings were categorised as ‘being scared’. ‘Being scared’ became a major category, elevated to a concept that encompassed a number of other categories closely related to the children’s ‘being scared’. Related categories therefore became subcategories of ‘being scared’ and these were: ‘not knowing; ‘being alone’; ‘seeing adults who were patients’ and ‘having an operation’.

All of the children in the study expressed some level of fear or anxiety about their surgery and admission to hospital. The children described feeling nervous, they were scared and the situation was ‘scary’ (Boy, 7yrs) or ‘really scary’ (Girl, 8yrs) for them. The children were frightened about a wide range of things associated with their hospitalisation and surgery and the following quote indicates that for one child in this study, sometimes, *everything* was frightening.

Like if it was going to really hurt me. I was scared and didn’t know whether mum would be there for me and everything [child’s emphasis] (Girl, 12yrs).

The situation could at times be quite overwhelming for children. When asked what it was like when she first knew she would need to go to hospital after sustaining a fracture to her forearm, one girl said she was:

Scared, I was screaming (Girl, 11yrs).

This child was in pain because of the fracture to her arm, but the need to go to hospital for treatment was a cause of increased distress and fear:

...[I was] nervous... it’s really scary on the first day’ (Girl, 11yrs).

Anxiety was not only experienced by children who were admitted to hospital for the first time. Children who had previous admission/s for surgery also expressed

nervousness about being in hospital and having surgery. One boy, aged 10 years, who had previous surgery said:

I was kind of nervous (Boy, 10yrs).

Although this child had some understanding of what to expect and what was happening, based on his previous experience of surgery, he was still nervous about his situation. Another child, who also had a previous admission to hospital, wrote in the story he provided that going to hospital for surgery was 'nerve breaking' (Boy, 11yrs):

A photograph of a child's handwritten text on lined paper. The text is written in dark ink and reads: "To Karen, before I went to hospital it felt are bit Nerve breaking for me because of the operation. In Hospital". The handwriting is somewhat cursive and shows signs of being written by a child. The word "are" is used instead of "a", and "Nerve" is capitalized. The sentence is cut off at the end.

To Karen, before I went to hospital it felt are (sic) bit nerve breaking for me because of the operation (Boy, 11 yrs).

These two children had experiences of admission to hospital and surgery to draw upon, because of their previous admissions and they referred to these when talking about their feelings about hospital. However, they clearly had anxieties and concerns that were specifically related to their current admission.

Previous studies have shown that the effects of hospitalisation on children can be temporary in nature or longer term and include aggressive behaviour, anxiety, withdrawal and an increase in separation anxiety, enuresis, altered sleep and appetite problems (Kirkby and Whelan 1996, p66, Peterson et al. 1997, p335). Causes of anxiety for children have been described under five domains in a noted study by Visintainer and Wolfer (1975) as 1) physical harm or injury from pain, mutilation or even death; 2) separation from parents; 3) fear of the unknown and unfamiliar; 4) uncertainty about accepted behaviours in hospital and 5) loss of control, autonomy

and competence (p187). Other aspects of hospitalisation that have been identified to cause stress include unfamiliar places, faces and routines; medical jargon; shame and witnessing parental anxiety (Justas et al. 2006).

The findings of this study reflect those from other works. Coyne's (Coyne 2006a) grounded theory research also related in part to children's experiences of hospitalisation (Coyne's work also considered the perspectives of parents and nurses). Coyne found that children identified a range of concerns and fears about their hospitalisation that included fear of separation from family and friends, the unfamiliar environment, investigations and treatments and loss of self-determination (Coyne 2006a, p328).

Research with children conducted by Curtis (2007) found that hospitals were not of themselves inherently scary or unfriendly places for children and that it was the experience of painful procedures that transformed hospitals into places that were frightening. The literature also reports that for some children, needles are symbolic of hospitalisation (Schechter et al. 1997, p891). This current research found pain caused by their surgery, and pain associated with procedures such as injections, was an important cause of the anxiety experienced by children. Nevertheless, this study found that children's anxiety about hospitalisation was not limited to pain as the sole cause for their anxiety and that their anxiety was caused by a number of factors, as outlined in the next sections.

Research by Carney et al (2003, p36) on children's views of hospitalisation showed that children's anxiety around hospitalisation increased with age and that girls were more anxious than boys. Further, children's anxiety occurred mainly when children were apprehensive about coming into hospital rather than during their stay, suggesting that children were comfortable with being in hospital once their initial anxieties were allayed. In contrast, findings from this study are that anxiety was expressed by all the children in the study, both boys and girls. The children also described feeling anxious across the period of their hospitalisation, not just about apprehensiveness and uncertainty they experienced prior to their hospitalisation, although this was indeed a part of the children's experience.

In summary, fear and anxiety, expressed in this research by the concept ‘being scared’ was a concept within the phenomenon of admission and surgery as experienced by the children. There were a number things that gave rise to the children’s fears, and children’s fears were also influenced by their previous experiences.

Not knowing

‘Not knowing’ represents the strangeness and unfamiliarity of the children’s situation and the anxiety that this caused them. ‘Not knowing’ was identified as a sub category of ‘being scared’, and ‘not knowing’ itself was seen to give rise to the children ‘being scared’. The children did not always know what their hospitalisation and surgery would entail and they did not always feel in control of their situation. This resulted in feelings of vulnerability and incompetence, reflected in the following quotes from the interviews:

I didn’t know what was going to happen (Girl, 8yrs).

I didn’t know because I didn’t... haven’t been in there (Boy, 7yrs).

Being in hospital and undergoing surgery were largely unfamiliar experiences for children and the children said their anxieties were partly a result of the uncertainty, the strangeness and unfamiliarity associated with their hospitalisation and surgery.

The children who had no previous experience of admission to hospital did not know what to expect, or what was going to happen to them and they were unfamiliar with the hospital environment. Children also spoke of not knowing anyone (family or friends) who had undergone surgery before. Not being able to draw on the experiences of people close to them meant children felt less able to understand what was going to happen to them.

I was a bit scared and spooked about it... because I’d never had an operation before (Girl, 8yrs).

I felt a bit scared because I never had an operation or nothing before. And no-one in our family, like that I knew of, had been in or had an idea of what was going to happen and that (Girl, 12yrs).

The findings of this research around ‘not knowing’ reflect the findings of other studies, including the study by Visintainer and Wolfer (1975) that found the unknown and unfamiliar were important sources of fear in the children’s surgery experience. Research with children conducted by Smith and Callery (2005) on children’s information needs for elective surgery found that the children in that study knew little about hospital, their admission or their surgery. Similarly, in a more recent study with children aged 6 – 9 years having day surgery (Wennstrom et al. 2008), children were found to experience anxiety and distress because they did not know what to expect of their approaching surgery and they could not imagine what would happen to them. This was expressed as ‘an unknown reality’ by the authors (p101). In this current research, the gerund ‘not knowing’ describes this part of the children’s experience.

Within the hospital environment the children came in contact with a large number of people who were strangers to them. Another aspect of the children’s not knowing, therefore, was in relation to the numbers of people they both saw and met in hospital who they did not know. The children expressed feelings of shyness and unease that was generated as a result of this, particularly around the time of their surgery.

I: How did you feel when you were going to go for your operation?

C: Umm shy.

I: You felt a bit shy did you? Why did you feel shy?

C: Umm because there were heaps of doctors (Boy, 8yrs).

I: And what was freaky [in reference to the theatre environment]?

C: That um because there’s lots of people there which I didn’t know (Girl, 8yrs).

Observational research by Wollin et al (2003, p73) also found that numbers of people at induction of anaesthetic proved overwhelming for some children. Coming into contact with large numbers of strangers added to the children’s ‘not knowing’.

When the children were not included in discussions about their care, they were effectively excluded. This would serve to make them feel further silenced and disempowered, and increase their sense of ‘not knowing’. The following memo is from a period of observation within the Paediatric Unit, and relates to a child who was seen post tonsillectomy and adenoidectomy:

Memo

The doctor came to review the 9 year old girl who had a tonsillectomy and adenoidectomy the previous day. She was resting in bed and her father was in attendance. If all was well, she would normally have been discharged following this review, but there was a small amount of continuing bloody ooze from her nose and so she would remain in hospital a little longer. The doctor sought her assistance as he went to examine her. He asked her to open her mouth and he gently inspected her nares. On finishing his observations, he said to the child that she was a good girl and then he turned to speak to her father about what he had found. He did not include the child again until he waved her goodbye. Throughout the time of this consult, the child did not say a word 3.8.2008.

That children are often excluded from discussions about their condition and treatments has been identified in previous research (Alderson 1993, Alderson et al. 2006, Coyne 2006b, Smith and Callery 2005). As Coyne (2006b) states: '[i]t appears that the practice of speaking with children, listening to them and involving them in the decision-making process is not widespread among health professionals' (p62). When discussions are between adults, such as those between healthcareers and parents, age appropriate language suitable for children is not used. The result is that children's own understandings about what is happening are not increased.

This section has described how the sub category 'not knowing' relates to the concept 'being scared' because not knowing gave rise to anxiety for the children.

Being alone

'Being alone' refers to both the children's fears of being abandoned as well as their feelings of being left all on their own and was a sub category of 'being scared'.

'Being alone' is reflected in the quote from one child:

All I wanted was mum (Girl, 9yrs).

This section outlines 'being alone' and describes the children's experience of being scared of being left alone as well as of being alone in hospital. Being alone was a concern for the children during the time they were in the hospital, but particularly around the time of their surgery. The notion of being alone was found to be closely linked to their feelings of anxiety as well as sadness, as demonstrated in the quotes that follow. Children who were to be admitted to hospital for the first time were frightened that going to hospital would involve being separated from their parents,

and when in hospital, all the children reported feeling 'left alone' and lonely, particularly when parents were not in attendance.

I: What didn't you like about it [going to hospital], what did you think?

C: It would be going away from my mum and dad (Boy, 6yrs).

When I was in hospital I never used to like talk to no-one (Boy, 6yrs).

When a child who had a parent in attendance during most of her admission was asked what she thought it would be like should her parent not be with her, she responded:

I: And just in case they [parents] weren't able to be here, what would it be like?

C: Sad... because I won't have no-one to look after me and see me, only the nurse and the doctors (Girl, 11yrs).

Fear of their surgery included fear that they would be alone when they woke from their anaesthetic. One mother spoke of the fears her child had at this time:

Mother: she was scared that she was going to wake up and no-one's going to be there. When I went in there she was very, very scared, she was crying cause we weren't there [mother's emphasis]. (Girl, 9yrs).

One child, who was aged 6 years, said that one of the hardest days he experienced in hospital was the day his dad had to go to work. His father was gone all day, and did not return til the night. The child felt 'left alone', even though he was in the middle of a busy paediatric unit, in a four bed room shared with other children and their families, and with a nurse to care for him.

I: Can you tell me what kind of things have been hard in hospital

C: Umm, having dad have to go to work and me being left alone (Boy, 6yrs).

Children said that when their parents weren't with them, they were alone:

I: So who looks after you when mum goes away?

C: Nobody. I just talk to meself (Boy, 8yrs).

The children's feelings about being alone went hand in hand with the anxieties they felt about being in a strange and frightening environment and their feelings of helplessness.

It was noted that parents of some children who had previous experience of hospitalisation did not always sleep on the hospital ward overnight. Some slept in parent accommodation or, if they lived in close proximity, in their own home. However, parents of children who did not have previous experience of surgery all slept on the ward overnight, generally by their child's bed. Where parents stayed overnight was dependant on their child's age and condition, whether the child had previous admission/s to hospital and other family commitments. Further, some children expressed the need for a parent to be with them at all times, because of their high levels of anxiety. The need for their parents to be in constant attendance for children who had no previous admission can be seen to reflect the children's reliance on their parents in a situation where they are unfamiliar and do not know what will happen to them.

Loneliness is described as a state arising from a sense of yearning for another person that is also associated with feelings such as sadness and helplessness. Loneliness involves the circumstances of aloneness as well as the feeling of sadness (Cassidy and Asher 1992, p351) and research has found that even very young children can and do experience loneliness (Kirova 2006, p130). Hospitalisation has been recognised as a cause of situational loneliness for children (Heinrich and Gullone 2006). This form of loneliness is experienced by those who previously had satisfying relationships, but who are confronted with a specific crisis or life transition that disrupts these relationships (Heinrich and Gullone 2006). Children's concerns about being separated from parents and siblings, their home environment and friends have also been described in other studies (for example Coyne 2006a, Carney et al. 2003, Forsner et al. 2005). As early as 1943, children's separation anxiety as a result of hospitalisation was described in a study conducted by Edelson (1943). Edelson's study identified varying degrees of disturbance in children and made practical suggestions for addressing the children's anxiety including visiting for children in hospital but his work was largely ignored.

Seeing adults who were patients

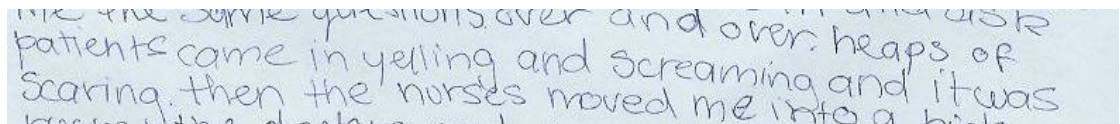
'Seeing adults who were patients' and the experience of being cared for alongside adults was identified as a cause of distress by children and was a sub category of 'being scared'. This study was conducted in a general hospital, and there were times that the children were cared for alongside adults. For example, children admitted via the Emergency Department would be in areas where adult patients were also being cared for.

I: When you came into hospital you saw some people, who did you see?

C: Really sick people, like with broken arms and stuff like that

I: And what did you think about that?

C: Um one was hurt and stuff like that (Girl, 8yrs).

A photograph of a child's handwritten text on a piece of paper. The text is written in blue ink and reads: 'patients came in yelling and screaming and it was scary. then the nurses moved me into a bed'. The handwriting is somewhat messy and childlike.

*heaps of patients came in yelling and screaming and it was scary (sic)
(Girl, 12yrs).*

The children found the sights and sounds of adult patients who were themselves in distress, frightening and disturbing. These things added to what was already a stressful and frightening time for the children. The experiences of these children reinforce the need for children to be cared for in paediatric-specific areas within health care settings. Although there was a dedicated area established for the care of children in the newly commissioned Emergency Department, at the time of this research, the paediatric area was not open because of limited resources. The dedicated area has since been opened and children who present to the Emergency Department are now cared for in an area that is separate to adults.

The stress this situation causes children has been identified in other studies with children as participants. Children reported similar concerns about the lack of child friendly spaces in Emergency Departments in studies around their experience of health care in research by Curtis et al (2004). *The (Australian) Standards for the Care of Children and Adolescents in Health Care* (RACP 2008) state that separate waiting and treatment areas for children and adolescents should be provided in emergency and outpatient departments, intensive care units and surgery units. Whilst

one paediatric specific area within the hospital opened during the course of this research, another was closed. Closure of the paediatric recovery area is described in the following memo:

Memo

At the surgical team meeting this week, I learnt that the dedicated recovery area for children had been disbanded because of recent refurbishment and claims of safety concerns. Children are now recovered from their surgery in the same area as adults. I wondered who had been responsible for this decision. Were the children's interests considered as a priority in the decision making process? Was it not possible to work to establish an area that was safe for children to recover in, rather than disband it altogether? 16 May 2009.

Having an operation

'Having an operation' refers to when the children were in the immediate perioperative period, that is around induction of anaesthetic to recovery from anaesthetic. The children experienced the highest levels of fear and anxiety around the time of their surgery, including induction of anaesthetic and recovery and 'having an operation' was seen to be a sub category of 'being scared'. Their experience around the time of their surgery was a most significant time for the children: this time stayed in their memories, gave rise to strong feelings and had real emotional force, as evidenced in the following quote:

Well I cried when I was going up there because I didn't want to go up there and have an operation because I didn't know what it would feel like. Because it was my first time I had my appendix out (Girl, 8yrs).

Children expressed fears about going to sleep, of waking during the surgery, as well as not waking after their operation.

Then I was scared cause I didn't know whether would I go to sleep or not go to sleep, thinking it might not work and I would still be awake (Girl, 12yrs).

Like I didn't know if they'd put me to sleep and all that stuff and I thought I wasn't going to wake up (Girl, 9yrs).

I: How did you feel about having to go and have the operation?

C: Scared

I: And what were you scared of?

C: Um ... going to sleep (Girl, 8yrs).

C: I felt like a bit sore and all I wanted was mum and stuff (Girl, 9 yrs).

I: Can you tell me what that's like when you go to have your operation?

C: Oh I was kind of nervous. I felt like kind of nervous (Boy, 10yrs).

All of the children participating in the study, including those who had previous experience of surgery, expressed anxiety and fear about their surgery and undergoing anaesthetic.

In the following quotes, children describe their sense of disorientation and of not knowing where they were on waking from their anaesthetic:

I: do you remember waking up after you had your operation

C: yes. I didn't really know where I was

I: did someone tell you where you were?

C: Yes

I: What did they say?

C: She [the nurse] said I was in the waking up room (Boy, 6yrs).

I: So what were you scared about?

C: ... I thought I was still like in having the operation

I: OK so when you woke up you didn't know whether you'd finished your operation. Is that right? Who told you that you'd finished your operation?

C: Nurse told me to wake up and I thought that I was still in the operation (Girl, 9yrs).

In the periods of observation in the post anaesthetic recovery area, I observed children as they emerged from their anaesthetic. On waking, they demonstrated that they were confused and anxious. These feelings may be common to adults as well as children who awaken from anaesthetic. However, children who have no previous experience of surgery are less able to rationalise that the strange place they are in is a recovery area and that their surgery is indeed over. The children were put at ease when the nurse caring for them provided them with information and reassurance that their operation was over, and that they were 'all right' and there was a clear relief of their anxiety when reunited with their parent/s.

Their parent's presence was very important to the children at this critical time as one child explained:

I: Was your mum or dad with you when you went to sleep?

C: Yeah this time and last time, last time it was my dad and this time was my mum

I: Ok was that a good thing

C: Yes

I: And why was that, can you tell me

C: Cause having somebody that you, having your family there to see you go to sleep and they say its going to be all right and stuff (Boy, 10yrs).

The children's need for their parents at the time around their surgery links to parental presence, discussed in more detail in the next chapter.

The need for surgery is recognised as providing cause of anxiety for children. In addition to the fears previously identified around admission to hospital, fear and anxiety that are associated specifically with the experience of having surgery include fear of the unknown; anticipation of pain and discomfort; fear of surgery itself; injections; separation from family and other significant people in their lives; incapacitation; loss of control and of independence; falling behind in school; change of body image; and fear of death (Cauma et al. 2000, p782, Coyne 2006a, p327).

Similarly, identified risk factors for preoperative anxiety in children compare to those for children who experience admission to hospital. They include the child's age and temperament; their previous medical experiences (including previous surgery and hospitalisation and medical encounters of 'poor quality') as well as parent's anxiety state and personality (Kain et al. 2006, p631). The factors are also influenced by information from relatives and friends and media depictions (Manwarren and Fledderman 2000, p3). Factors that have been found to contribute to children's negative experiences include their unfamiliarity with the perioperative setting; threatening medical equipment; painful procedures; as well as lack of control over events (O'Connor-von 2000, p335).

Approximately 60% of children undergoing surgery are said to develop 'significant' fear and anxiety before their surgery (Kain et al. 2002, p28, Wollin et al. 2003, p69). Although anxiety and fear is important to recognise for itself, the impact of this fear and anxiety for the children is also of significance. High levels of preoperative anxiety have been found to have effects that can impact further on the child's experience. For example, preoperative anxiety can lead to lower levels of co-operation in the period of induction of anaesthetic; postoperative excitement in the

recovery room; delayed postoperative recovery; increased incidence of pain and analgesic requirements; increased incidence of nausea and vomiting and increased intravenous fluid requirements; and an increase in the number of days a child has to stay at home (Kain and Caldwell-Andrews 2005, p609).

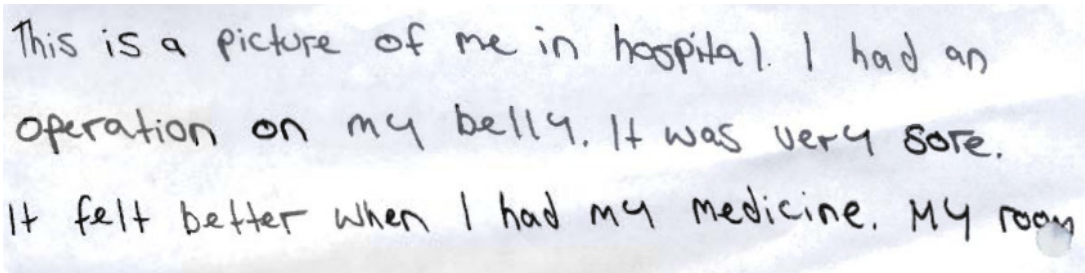
A study by Kain and others (1996) found that children 7 years and older were more anxious in the immediate preoperative period than children aged 4 – 7 years. Stress related symptoms associated with hospitalisation, and specific to children between the ages of approximately 7 to 12 years, include anxiety problems, depressive symptoms, stomach-ache, headache, secondary enuresis, or encopresis (Hagglof 1999, p73). Children can express their anxiety in this situation verbally, behaviourally, subtly or explicitly (Kain et al. 2002, p29). In this study the children said they talked about their fears with their family members, including parents and grandparents, and some of the children also displayed their fears through behaviours like crying.

The concept ‘being scared’ has been discussed in this section, and ‘being scared’ encompasses the subcategories of ‘not knowing’; ‘being alone’; ‘seeing adults who were patients’; and ‘having an operation’. The discussion now moves to the next major concept of the phenomenon, ‘hurting’.

Hurting

The concept ‘hurting’ refers to the emotional, physical and social elements that constituted the children’s experiences of pain. Hurting is expressed as a gerund in order to preserve the sense of action associated with this category. The concept ‘hurting’ incorporated the sub categories of ‘having needles’ and ‘experiencing pain’.

Children used words such as ‘sore’ and ‘hurt’ to describe their pain, and the following quotes provide examples:



This is a picture of me in hospital. I had an operation on my belly. It was very sore. It felt better when I had my medicine. My room

This is a picture of me in hospital. I had an operation on my belly. It was very sore. It felt better when I had my medicine (Girl, 8yrs).

Like, umm sore. Sore (Boy, 8yrs).

When you wake you're kind of sore, yeah and having, feeling this sore feeling sort of stuff (Boy, 10yrs).

The International Association for the Study of pain states that 'pain is always subjective. Each individual learns the application of the word through experiences related to life' (International Association for the Study of Pain 2009). The definition emphasises the person focused and subjective nature of the experience. The importance of healthcare professionals understanding the child's experience of pain from their perspective is also articulated in the literature: 'the answer to understanding a child's pain comes from the children themselves not from us (medical or nursing professionals) blindly applying adult perceptions to their world' (Lord Mackey 2000, p56). If pain is to be recognised as a subjective experience for children, then the child's own description of pain is essential, because only the child can accurately describe his or her own pain.

The children participating in this study described their pain experiences during their time in hospital, both preoperatively and postoperatively. Pain was experienced as a result of their illness condition, procedures such as insertion of intravenous cannula and as a result of their surgery. In addition, preoperatively they expressed anxiety and fear about anticipated pain they expected to experience in the postoperative period. Findings from this current study were that children were able to understand the causes of their pain and also had the verbal skills required to describe it. It was apparent that the pain they talked about was temporally close to them, as the interviews took place around the time of their surgery, and their answers were shaped by this experience. These findings were similar to those from research by others who explored pain in children (Kortessluoma and Nikkonen 2004, Woodgate and Kristjansson 1996a). For example, previous studies have identified that children of similar ages to participants in this research were able to understand the concept of pain; its causes and consequences as well as the sensory, cognitive and emotional

characteristics of pain (Kortessluoma and Nikkonen 2004). Pain is a unique, complicated and sometimes all consuming experience for children and a number of things affect the way children experience pain. Their experience is shaped by age, cognitive and emotional development, previous pain experiences, social, behavioural, physical and contextual components (Carter 2002, p29, Kortessluoma and Nikkonen 2004, p212).

Having needles

‘Having needles’ was a sub category of ‘hurting’ and refers to the procedural pain associated with injections and the insertion of intravenous cannulas. The insertion of an intravenous cannula is recognised as the most distressing part of hospitalisation for many children, and the most feared part of that experience (Gordon et al. 2002, p2, Uman et al. 2006, p1, Duff 2003, p931). Having ‘needles’ was identified by the children in this study as one of the things they were frightened of and disliked most:

I: What were you were scared about?

C: Umm. About putting the needles in me hands (Boy, 8yrs).

One child said the experience of having a cannula added to her anxiety around her surgery:

A bit scary... because of an operation and stuff, because of all the needles (Girl, 8yrs).

For children in the study, the experience of intravenous cannulation was traumatic. The following extracts specifically relate to the pain the children experienced with the insertion or the ongoing presence of intravenous cannulas. In the next extract, the child talked about the cannula inserted at induction of his anaesthetic. He understood it was required for administration of the anaesthetic, and that this was a painful procedure. He found its continuing presence painful and ‘annoying’, and that it also hurt more on removal:

... having the needle when they put you to sleep. they kind of hurt. Hurts and the annoying thing was keeping the thing in my hand, that was really annoying especially when they take it out because it kind of hurts it as well (Boy, 10yrs).

In the following quote, a child says he felt a stinging with the insertion of the cannula (the needle). The reason for the cannula was to administer the anaesthetic.

I: What was that like?

C: Um stinging

I: When did it sting?

C: When he put my needle, the needle in...

I: And what did they do that for?

C: Put me to sleep (Boy, 7yrs).

Another child described the pain of cannula insertion and also how she held her mother's hand to help her cope with that pain:

C: ... before when I didn't have the drip they gave me a needle um near my elbow

I: Right and what was that like?

C: Um it hurt and I squeezed my mum's hand (Girl, 8yrs).

Injections and insertion of cannula were the cause of physical pain, but there were also emotional and cognitive aspects to them, as the quotes from the children demonstrate. The skin and body surfaces can be viewed as a definer of body territory, and as a result, of self. Intravenous cannula, injections and surgery all breach this boundary and so represent a threat or an assault on the sense of self. The children in this study were all faced with these perceived threats to their self, as they were all subject to these kinds of breaches. The effects of hospitalisation and procedures such as injections on children and their sense of self are described by Alderson (1993):

A minor procedure becomes for many young people a major symbol of everything they fear about hospitals. In fact and fiction, the skin is usually penetrated either for medical reasons or to harm or kill... The skin is the only fragile barrier between the tiny self and the otherwise infinite not-self. Patients' sense of self is threatened and constrained in hospital; they have left at home their possessions, friends, familiar life, freedoms and everyday social identity. Those without a secure sense-of-self are liable to feel lost and overwhelmed; the needle reinforces these feelings when it breaks through the division between self and not-self (p179).

Alderson's claim that 'minor' procedures like cannulation are important symbols of things that children fear about hospital is borne out in this study.

The following drawing (Figure 8) is by a 12 year old girl and depicts the child receiving an injection in her arm (her intravenous cannula was sited in her cubital fossa). As previously discussed, a danger with the draw and write technique is of over-analysing the drawings and reading too much into them. In addition, there needs to be caution around translating children's ideas into 'adult' concepts and theorising (Williams and Bendelow 2000 p57). Superimposing my own thoughts onto what this child was trying to communicate presents some risk. There was not the opportunity to check with this child her own meanings - in the accompanying story, she says the nurse took a blood test and put a needle in 'for my drip'. Caution is therefore needed in interpreting this drawing. In the drawing the injection is the focus and is given a central position in the picture. The child is rendered almost invisible because there is only the outline of the child and her face is not depicted. The child's body has a passive appearance, and there is a real sense this child is not in control of this situation. In contrast, the drawing of the nurse is completed in colour; the nurse is represented in a very casual pose, hand in pocket with her legs crossed. The nurse is looking away from the child and appears disengaged and quite removed. In addition, the only point of contact between the child and the nurse is the needle tip itself.



Figure 8: Drawing of child and nurse (Girl, 12yrs)

The following memo presents my thoughts when I received the drawing and story from this girl.

Memo

When I opened the self-addressed envelope and saw the drawing and story, I was quite surprised. The story is 2 full A4 pages of closely handwritten work, filled with her experience of going to hospital and having surgery. But it was the drawing that captured my immediate attention. The drawing is fairly simple but it is really intriguing. The child's body is just an outline and the child's head is not included in the picture – did she 'run out of page' because of scale, or is there something more to the image and the story it tells? The child is drawn in a very passive pose and the way the child is depicted is in stark contrast to the colour used in the drawing of the nurse – who looks so disengaged and uninterested. There seems to be a real disconnection between them. The needle is given the central focus in the picture and as well as her thoughts about the needle, I wondered about this child's experience of feeling cared for by the nurses 30.3.2007.

Experiencing pain

'Experiencing pain' refers to the children's own experience of pain and is a sub category of 'hurting'. Pain was clearly an important factor in the children's interpretations of their illness and the treatments that they received. In addition, it can be interpreted from the children's reports of pain that the pain experienced by them may have been undertreated. Research findings are that children continue to experience unrelieved pain post-operatively and that their pain management remains sub-optimal (Twycross 2008, p3205). Pain causes unnecessary suffering and presents a burden that diminishes coping resources required for recovery and healing (Ellis et al. 2001, p268). Research suggests nurses believe that pain is to be expected *and* accepted (Woodgate and Kristjanson 1996b), despite the presence of evidence, standards and guidelines that indicate otherwise. Research has also found that children perceive the nurse's role in pain management as largely a technical role, that consists of administration of medication (Woodgate and Kristjanson 1996b). The children's reports in this research demonstrate that they perceive an important feature of the nurse's role is in relation to pain management and medication administration.

I: Can you tell me what they [the nurses] do?

C: They give you painkillers and stuff, sometimes tablets, sometimes liquid (Boy, 10yrs).

The participating children trusted that the nurses would treat their pain, and they considered this to be an essential part of the nurse's overall role in caring for them.

The children identified a number of strategies they employed to help them with the pain that was a result of their condition, procedures or their surgery. These strategies were important coping mechanisms they employed to deal with pain that was a major concern for them within the experience. How children coped with their pain is discussed in detail in the next chapter as part of 'bouncing back'.

The findings to date have related to the concepts that have accounted for the more negative aspects of their experiences, that were included in the concepts of 'being scared' and 'hurting'. However, the children also identified the things that were positive or those they enjoyed and these are captured within the concept of 'having fun'.

Having fun

'Having fun' was identified as a concept and refers to the positive aspects of the children's experiences and those things the children enjoyed about their hospitalisation. It was found that although all the children expressed anxiety and fear about their hospitalisation and surgery, they also expressed positive feelings about going to hospital and having an operation. 'Having fun' incorporates the sub categories of 'play and laughter' and 'feeling special'. The children described aspects about going to hospital that were fun, and in order to present the phenomenon in its complexity, it was important to represent these positive aspects of the experience as well as those things that caused children to experience negative emotions. For example, children said interactions with nurses, watching television, playing the computer games and visits from the hospital clown doctors were fun.

Play and laughter

'Play and laughter' was a sub category of 'having fun' and refers to the normal development needs of children for play as well as the therapeutic effects play and laughter had for the children. The children talked about the play activities they enjoyed – both before and after their surgery. According to the children, activities they enjoyed included the following:

Watch TV and do a word search (Girl, 8yrs).

You could read books and stuff and you could watch TV (Girl, 8yrs).

I like the school in hospital... you have the playroom and that (Girl, 12yrs).

I just like watching DVDs and playing games and stuff (Girl, 9yrs).

When one child was asked how he felt about going to hospital he answered:

Oh kind of OK because like there's the TVs, yeah and the food and stuff... But I'm also looking forward to the computer games coming around in the afternoon. (Boy, 10yrs).

This child remembered from his previous admission for surgery that computer games were available for the children on the ward in the afternoon, following the rest period. Other things the children enjoyed included the hospital school program and play area:

I like school in the hospital because just because you're missing out that doesn't mean like you can't learn and do other thing like you have the play room and that (Girl, 12yrs).

(Recall that missing out on school was a recognised cause of anxiety for hospitalised children).

For the children, play was fun and to an extent, it was as simple as that. Play that is simply fun is in itself a therapeutic and worthwhile activity that is of value for hospitalised children (Fereday and Darbyshire 2008, p8). Play as described by the children provided them with a positive means of relieving their boredom and passing time in a pleasurable way.

Play for children is acknowledged as a vital part of their everyday lives and its importance is well recognised in child development theory. Play, as we have seen, continues to have importance for the child who is hospitalised. The *Platt Report* (1959) and reports and statements since then have made clear recommendations for play to be provided in hospital to maintain the emotional well-being of hospitalised children (Nicholson and Clarke 2007, RACP 2008, AWCH 2002).

As well as play activities, the children described interactions with staff based on humour and laughter in both their interviews and writings. In the following quote, the child says that one of the things he enjoyed about his interactions with the nurses was that they made him laugh:

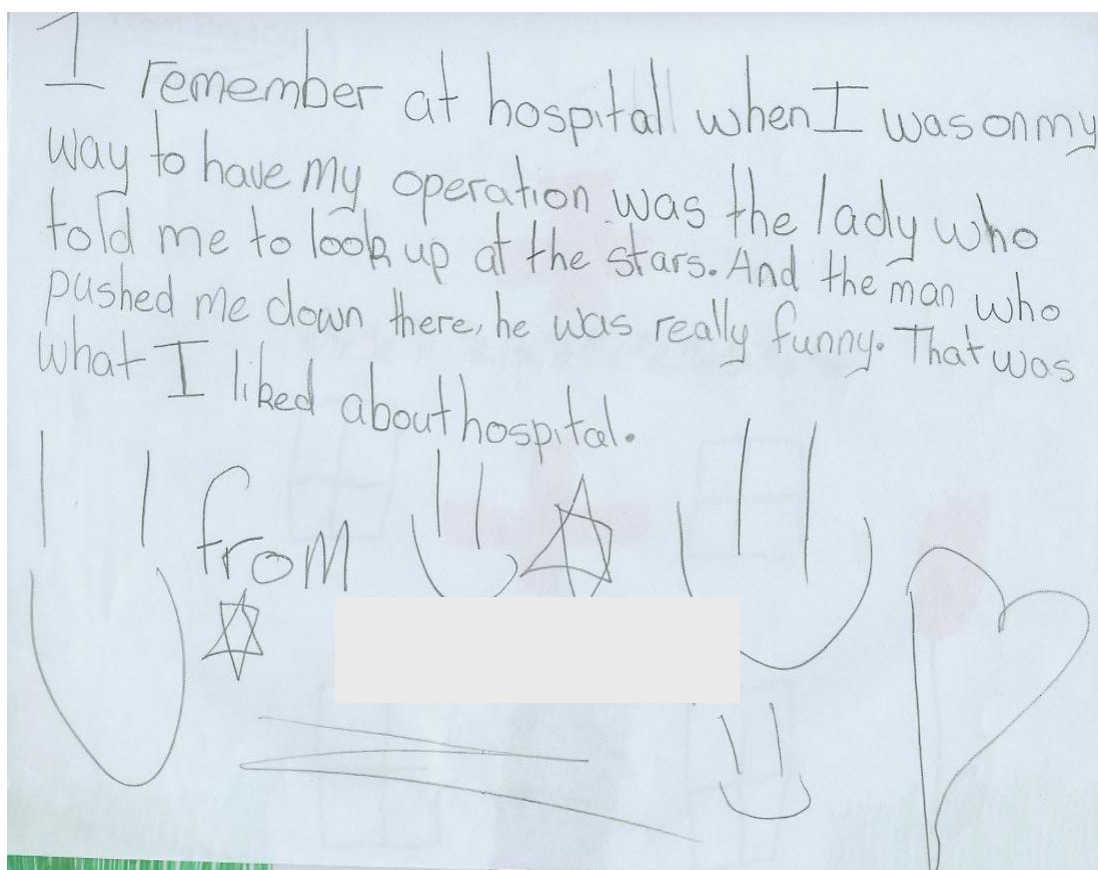
I: What does a nurse do when your mum might not be there?

C: She makes me laugh

I:... Ok what kind of funny things, can you remember any?

C: Umm pulls funny faces and stuff (Boy, 8yrs).

In the following story written by one child is her description of being transported to theatres by the orderly and nurse.



I remember at hospital when I was on my way to have my operation was the lady who told me to look up at the stars and the man who pushed me down there he was really funny. That was what I liked about hospital (Girl, 8yrs).

When talking to me about her story, the child explained in more detail what had happened when she was being transferred to theatre. She thought the orderly (the man who pushed her bed) was funny because he joked about getting 'his bottom

caught in the lift doors'. The nurse (the 'lady') pointed out the stars on the ceiling. The ceilings from the paediatric ward to the operating suite are lined with stars, and children are encouraged to follow the trail of stars as a form of distraction on this journey (these stars were also depicted in some of the children's drawings). The child also told me in interview, that she cried on her way to theatre and that she didn't want to go. Her experiences, however, were affected in a positive way through her interactions with other people. Her memories of this stressful time were tempered by the positive influences of those who provided her with support and used humour that was in effect a therapeutic intervention.

Of special note are the effects that all the people the children come in contact with can have on their experience: not just the nurses and doctors for example, but orderlies, cleaning staff, other patients and their families/visitors as well. In the story above, it was the orderly as well as the nurse who made a positive difference to the child's experience of going to theatre. That children's experience is impacted on by other staff, patients and their visitors is a finding in other studies exploring children's experiences of hospitals and healthcare (Curtis et al. 2004, p152).

Linked to this notion of interactions with others is that a number of the children made specific reference to their positive interactions with the hospital clowns.

I: What do you think about coming to hospital?

C: ummmm... mm.. fun

I: it's fun is it? What's fun about it?

C: The play station

I: What else is fun

C: Umm, there's some funny doctors (Boy, 8yrs).

I: Can you tell me some of the good things about being in hospital

C: Umm... the playstation,

I: Yes.

C: And doctors [clown doctors]

I: You liked the clown doctors did you?

C: They were real funny...They took pictures and pulled funny faces and done funny things with stuff and makes you laugh ...Yep they took a picture of me with a clown nose on (Boy, 8yrs).

Similar comments were made by others:

I: I think you said that the clown doctors came?

C: Yeah!

I: What was that like, can you tell me a little bit about that?
C: That was funny, it was fun, really fun (Boy, 10yrs).

As previously mentioned, when preparing for one interview with a child who had surgery for a fractured radius and ulna, the hospital clown doctors came into the room and spoke to us (p172 of this work). The clowns did a 'mock interview' with the child and 'Dr Fuss Pot' played the ukulele and sang the child a special song she made up about her. I was placed in a sling for a pretend broken arm, and covered in red dots by 'Dr Dotty'. The child clearly enjoyed the silly song and the antics of the clowns.

Clown Doctors parody hospital routines and help children feel less traumatised by medical procedures. Using various jokes such as oversize medical equipment, 'red-nose' transplants, 'cat' scans, humour checks and funny bone examinations, the clowns have fun with children, their families and staff. By exaggerating intimidating jargon and procedures, children's fears and anxieties are reduced and the children are empowered (The Humour Foundation 2010).

The therapeutic effects of clown humour are evidenced in the quotes from the children, and this finding is supported in the literature. The therapeutic effects of clown humour within children's units/hospitals have been recognised and children have been found to appreciate the beneficial effects of a clown visit during their hospitalisation. Clown humour has also been found to mitigate some of the negative effects hospitalisation has for children (Weaver et al. 2007, Vagnoli et al. 2005).

Reflecting the importance their family had for all aspects of the children's hospitalisation, family members were also found to have an important role in the children's experience of having fun. One child happily told me what his grandfather had said to him about how the surgeon would remove the child's tonsils:

Pop said they would put their hand up my butt and get them out. Pop said is your butt clean? [laugh] (Boy, 7yrs).

Children enjoy jokes based on 'toilet humour' including 'bottom' jokes and bodily functions. This child clearly knew his grandfather was joking about his operation and knew it to be silly. He also enjoyed the shocked response he got from those adults he

repeated this joke to – including my own reaction of pretend horror! The therapeutic effect of humour served to ease his anxieties and empowered this child.

Sensitivity in the appropriate use of humour is also required. One child in the study found the clowns a bit silly, and did not want to engage with them. Another child might find the comment of the grandfather, above, upsetting. An individualised approach to each child is important in the use of humour because of its personal and subjective nature. The clowns demonstrated sensitivity by moving on from the child who did not want to engage with them, but another child who had his photo taken with a red nose transplant and who was called ‘Bad Boy Bradley’ [pseud] by the clowns was thrilled and buoyed by his interactions with them. This sensitive use of humour with children has been described by Forsner (2005, p159) who described how it was fun for one child participant in their study to have jokes with staff, but for another child ‘it hurt inside’ because she felt staff were making fun of her.

Feeling special

Part of the children’s having fun was also being made to feel special and ‘feeling special’ was a subcategory of ‘having fun’. ‘Feeling special’ refers to the way the children felt special and some form of ‘kudos’ that set them apart from their friends and earned them the esteem and admiration of their peers. These feelings were reinforced as they were given extra attention, made a fuss of, and made to feel special by their family and friends. One girl said:

I’ve never had a friend that went in hospital (Girl, 9yrs).

Although another child had used similar words to indicate that they felt scared and did not know what to expect of their admission, this child spoke with a sense of self-importance. The fact that she was the only one amongst her friends to experience hospitalisation set her apart from her friends and gave her a sense of being special.

Children described talking to their friends and school mates about being in hospital. Some of the things they received whilst in hospital would be taken to school for ‘show and tell’ where they would talk about their hospital experience to members of their class.

I: When you went to school did you talk to your friends at school about going to hospital?

C: Yeah

I: What did you tell them it was like?

C: I said .. they go 'where did you go'. I go 'To the hospital'. And they go 'did you have an operation' and I said 'yes'. And people said 'did you have your tonsils and adenoids out'. And I go 'yeah' and they said 'I never want mine out'.

[Laugh]

I: What did you tell them when they said that?

C: I thought, 'well... when you have it out you feel really dopey and you want to sleep', and she goes 'oh that would be good for me!' (Girl, 9yrs).

When they were in hospital, children enjoyed visits from family and friends, who sometimes brought the children gifts and food treats:

I: Who came and saw you when you were in hospital?

C: My dad, my mum, grandmother and my aunties and stuff, and my uncles

I: Really, and what did they do when they came and visited you?

C: They bring you presents and stuff and give you balloons and stuff (Girl, 9yrs).

A child who had a previous admission to hospital referred to his positive experience of that admission, in terms of being made to feel special:

Last time I had some visitors come in and - some people I know come in and last time some of them actually gave me some lollies and stuff. That was really good (Boy, 10yrs).

One child had been told by his father that he would be able to have ice-cream while he was in hospital, and he would also have this treat when he went home:

I: What do you think you would do while you're in hospital?

C: Have ice cream and jelly... And when we get home dad will bring me a big block of ice cream! (Boy, 7yrs).

Other familiar, but special things the children looked forward to included television programs (sometimes a wider choice than they would have access to at home), and different kinds of food:

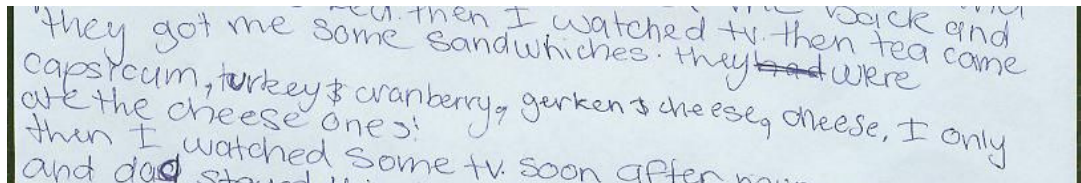
I: OK so the TVs good, you like that. And you like the food.

C: Yep

I: What do you like about the food?

C: Well there lots of yummy stuff like jelly and ice-cream and all that (Boy, 10yrs).

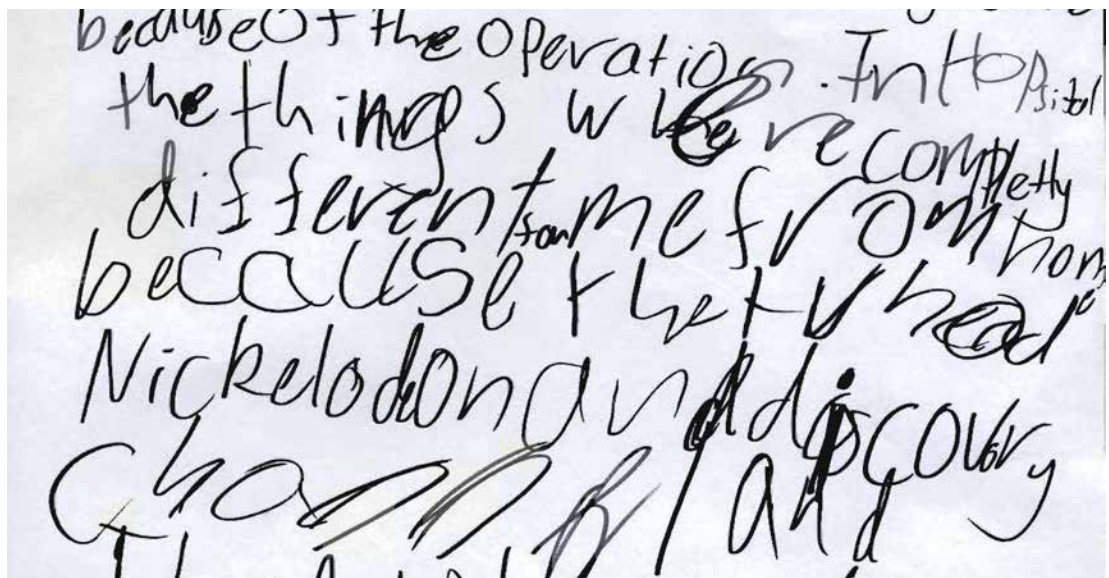
The following quote, however, indicates that sometimes things that were different and unfamiliar had a negative impact on the children. The choice of sandwiches served to this girl were not ones that she found appealing – except the cheese ones!



"they got me some sandwiches. they were capicum, turkey & cranberry, gerken & cheese, cheese, I only ate the cheese ones! then I watched some tv. soon after home"

They got me some sandwiches. They were capicum, turkey & cranberry, gerken [sic] & cheese, cheese. I only ate the cheese ones! (Girl, 12yrs).

In the following extract, the boy writes that things in hospital are quite different from home. Some of these differences, like the availability of television programs he enjoyed such as Nickelodeon (a children's television station) and Discovery Channel were things he found to be special.



because of the operation. In hospital the things were completely different from home because they had Nickelodeon and discovery channel.

In hospital the things were completely [sic] different for me from home because they had Nickelodeon and discovery channel (Boy, 11yrs).

The literature also contains views of children on things that they find special about their hospital experience, and these include visits, gifts, toys and games, the playroom and play (Forsner et al. 2005, p159, Carney et al. 2003, p32).

In summary, the children's experiences that formed the concept 'having fun' included 'play and laughter' and 'feeling special' and these were important to their overall experience of admission to hospital for surgery.

Conclusion

The analytic process revealed the phenomenon of children's admission to hospital for surgery, from their perspective. The phenomenon is described as an embodied experience of contrasts that included the concepts of 'being scared', 'hurting' and 'having fun'. The phenomenon as experienced by the children was outside of their normal world and was characterised by generalised feelings of fear, of not knowing and of being left alone. Children were distressed by some of the sights and sounds they were confronted with and the experience of having surgery itself was something that caused them increased anxiety. Pain was found to be a significant concern for children and this was caused by their illness condition, procedures such as cannulation, and their surgery. But there were things that the children enjoyed and looked forward to that were part of the phenomenon, so that having fun was also an important part of their experience. The things within the environment that were familiar to the children were identified by them as being positive aspects of the phenomenon.

In-depth exploration of the phenomenon from the children's perspective provides increased understanding of what it is like for children who are hospitalised for surgery. In doing so, the work contributes to the body of knowledge about this aspect of children's healthcare.

One of the major tasks for the children was to make sense of the experience. The next section of the work presents the processes the children were engaged in, in order for them to make meanings of the experience and to move on. If analysis of process had not been undertaken in this work, the study might risk being simply a descriptive one that did not progress to theorising, a criticism of a number of grounded theory

studies. The next chapter also includes the concept of ‘being held’ that was the context for children’s admission to hospital for surgery.

Chapter 7: The processes of ‘coming to know’ and ‘bouncing back’ and the context of ‘being held’

...bringing process into the analysis is essential. Process can be the organising thread or central category of a theory, or it can take a less prominent role. Regardless of the role it plays, process can be thought of as the difference between a snapshot and a moving picture. Each one pictorial form presents a different perspective and gives insight, but if one wants to see what happens, or how things evolve, then one must turn to the moving picture. Theory without process is missing a vital part of its story – how the action/interaction evolves (Strauss and Corbin 1998, p179).

This chapter is concerned with the processes the children were engaged in as they made meaning of their experiences and the conditions or context required for them to be able to do so. The processes of ‘coming to know’ and ‘bouncing back’ were the two processes identified from the conceptualisation and abstraction of the data. The context was described as ‘being held’ and consisted of a supportive and facilitating environment.

The processes the children were engaged in were conceptualised as processes in action – the moving picture Strauss and Corbin describe above. According to Strauss and Corbin (1998): ‘Process demonstrates the ability of individuals... to respond to and/or shape the situations in which they find themselves’ (p166). Analysing process assisted in the theorising that was integral to this grounded theory study of children’s hospitalisation for surgery as it helped to define and conceptualise relationships between experiences and events (Charmaz 2006, p136).

In analysing data for process the researcher is purposefully looking at action/interaction and noting movement, sequence and change as well as how it evolves (changes or remains the same) in response to changes in context or conditions (Strauss and Corbin 1998, p167).

This part of the work is congruent with the claim by Charmaz (2004) that a grounded theory study accounts for how participants construct meanings and actions in the phenomenon and delineate the conditions under which they do so:

To appreciate what is happening in a setting, we need to know what things mean to participants. Meanings render action and intention comprehensible. Actions can make implicit meanings visible. We observe our research

participants grappling with making sense of their lives, and then we grapple with them trying to do so (p981).

The children responded to as well as shaped the situation that was their admission for surgery. There was more than one process identified from analysis of the children's experience, so that there was no one *single* basic social process established in this study. Such a finding is consistent with the position of Charmaz (2006) in relation to basic social processes (p139). The processes identified through analysis of the data and conceptualisations were 'coming to know' and 'bouncing back'. 'Coming to know' explained how the children moved through their experience; accounting for the ways they responded to and interacted with their situation.

'Bouncing back' was the second basic social process and refers to how the children moved past the adversity that hospitalisation and surgery presented.

Coming to know

Part of the phenomenon from the children's perspective outlined in the previous chapter was the notion of 'not knowing'. Here, 'coming to know' describes the process the children were engaged in as they moved from not knowing towards knowing.

The concept 'coming to know' included the following sub categories: 'developing understandings' that in itself included the children's developing understanding of their conditions; of the language used within the hospital environment and of the role the child played as he or she experienced the phenomenon of admission for surgery. 'Coming to know' also comprised the sub categories of '[children's] participating in care' and their 'locating their selves' within the hospital setting.

Developing understandings

'Developing understandings' is a sub category of the concept 'coming to know' and relates to the development of the children's understandings of their hospitalisation and surgery. The children's developing understandings occurred over time and were associated with both time and experience. One child, interviewed after her surgery, said the following about her appendicectomy:

I: Can you tell me why you came into hospital?

C: Because my stomach was really sore
I: Where was it sore?
C: Just in the lower part, just near my leg
I: do you know what was wrong with your tummy?
C: Um I had appendix
I: You had appendix?
C: Appendicitis (Girl, 8yrs).

The child described the symptoms of her condition and could use the appropriate language to talk about it with me, and she was able to use correct medical terminology – *appendix* was corrected for *appendicectomy* to describe the actual condition.

A child who had a tonsillectomy and adenoidectomy because she experienced significant sleep apnoea told me why the procedure was necessary:

I: when did you know that you had to have an operation?
C: When they told me that my tonsils were really big and the middle bit were touching (Girl, 9yrs).

The following are other responses to questions about the children's surgery:

I: Can you tell me why you came to hospital?
C: Because I had to have my appendicitis [sic] taken out (Boy, 6yrs).

I: Can you tell me what operation you had?
C: I had one on my jaw because I got a cyst on my jaw and so... It was the second one I've had on my jaw. Last year, last May, I had one there. Well, it made a hole in there and that one kind of drained the cyst a bit. And this one was to take the cyst out (Boy, 10yrs).

When asked about the reasons for their admission to hospital, the children demonstrated differing levels of understanding of their condition and the surgery they required. There were instances when subsequent interviews indicated that the children had increased their understandings over time. Their increasingly correct or appropriate use of medical terminology was also evident, demonstrating a growing familiarity over time with this aspect of their experience.

One girl who was to have a laparoscopic appendicectomy told me about her surgery. The first two quotes below were in the interview conducted before her surgery. At

the time of this interview, she was in pain and frightened. Her father was in attendance.

I: So what are they going to do for you? What have they told you they would do?

C: Um that they were going to take something out of me

I: Do you know what that is?

C: I don't really know (Girls, 8yrs).

I: What did they say [about what they were going to do]?

C: That they were going to put me to sleep and take it out I think. Well have a look and then see if they need to take it out (Girls, 8yrs).

Although she understood she required surgery because her 'tummy was sore', she did not indicate that she had a detailed understanding about her condition or the procedure. The next quote from the same child was following her surgery. At this interview she was feeling well and happy and this interview was conducted without a parent being immediately present. She was able to use appropriate medical terminology (appendix) and describe in more detail the operative procedure:

I: So what was the operation that you had?

C: Well I had these 3 cuts well umm one there [pointing to sites on her abdomen], and one there, then one there, to get my appendix out (Girl, 8yrs).

This development of understanding is evidence of the process the child was engaged in over the period of her hospitalisation and surgery. This is a process of increasing familiarisation with hospitalisation and surgery, through the experience itself, the environment and the people she came in contact with. Personal knowledge, based on personal experience, is a powerful source of knowledge. Participation in everyday life can be viewed as a process of changing understanding in practice, that is learning, (Dilley 1999, p35) referred to in this study as 'coming to know'.

Children of this age group increasingly compare themselves with others, particularly their peers (Hagglof 1999, p73). One child talked to me about a friend of his who had several admissions to the unit around the same time as him for the treatment of a serious condition that had a very poor prognosis. Although he was very concerned about his friend, he clearly understood that his condition was quite different to that of his friend's, that his condition was similar to one his father had as a child of similar age, and he gave me an explanation of his own expected recovery and progress. In

the previous chapter, the children were seen to make comparisons between their experience and those of family and friends.

The children said they would not experience the same levels of fear if they were to require subsequent admission to hospital because they had gained increased knowledge and understanding through their experience:

I: If you had to go to hospital again, would it be as scary do you think?

C: No.

I: Why not?

C: Because I would know how it feels (Girl, 8yrs).

I: If you ... had to go to hospital again do you think it would be as scary?

C: No

I: Why wouldn't it be as scary?

C: Cause I've been there (Boy, 7yrs).

It was recognised that the children generally wanted to make sense of their world and what was going on, and one way of doing this was through being provided with information, about their hospitalisation, their illness or condition, treatments and surgery. This is congruent with their roles as active agents in the process they were engaged in. Their need to understand was described by the children, and it was also evident that this provided them with a positive coping strategy that they could then draw upon.

I: What did they [the doctors] tell you about that?

C: They just told me what they were going to do

I: OK so they did explain to you what they were going to do.

C: Yep

I: What did they say?

C: That they were going to put me to sleep and take it out I think (Girl, 8yrs).

Children received information about their hospitalisation and surgery from a variety of sources, including parents and other family members and medical and nursing staff.

I: How did you find out what happened [after surgery]?

C: Um one of the doctors told me and mum told me (Girl, 8yrs).

I: So when the GP told you that you had acute appendicitis do you know what that means?

C: Mummy explained what appendicitis would be about. Like so it was what mum told me. That like it gets inflamed and there is like poisonous stuff in the

middle and it can pop and then all this yucky stuff gets in your stomach (Girl, 12yrs).

One mother explained to her child how he would have a cannula inserted prior to his anaesthetic, because he had received little information about this process prior to his surgery from health professionals. Another mother said:

Mother: Well we just told her just to don't be scared and stay positive and nothing's going to happen to her, she's all in good hands (int 5a).

The father of one child had similar surgery to his son when he was a child. The son talked about some of the differences between his father's memories of hospital when he was a child and what it is like being in hospital in contemporary times.

My dad had this when he was a kid and he was in hospital and they didn't have like TV and stuff when he was a kid, and they only had one down the corridor and everybody had to go and watch (Boy, 10yrs).

The views of the children were that being provided with information helped them, that it helped to ease their anxieties to varying degrees and that it provided them understanding about the things that were happening to them.

I: Did the people who were helping you tell you what they were doing?

C: Yes

I: And how did that make you feel?

C: A little bit better (Boy, 6yrs).

I: And so did anyone talk to you about this [the iv]?

C: Um no um yes the doctor did

I: Was that a good thing or a bad thing?

C: Good thing

I: And why was that?

C: Because so I knew what it was all about and stuff

I: So knowing what it's all about helps?

C: Yeah (Boy, 6yrs).

Children's information needs for admission to hospital for surgery were considered in research by Smith and Callery (2005). The research found that the children had concerns and anxieties that largely related to pain and separation from their parents. The knowledge of children participating in their study (N=9) ranged from limited to substantial knowledge of being an inpatient. Notably, none of the children in the study by Smith and Callery had received direct information about their admission

from the hospital or health care professionals. Children were found to have obtained information about hospital from visiting others in hospital, from their parents or from television programs.

Similarly, knowledge the children in the current study had was received through various communication sources. The different information sources for children in this study included the information the children received from parents and grandparents, their friends and the media - the red cross in the child's drawing of the hospital (Figure 12) that comes later in this chapter (p192) is an example of this last source.

Participating in care

'Participating in care' was a sub category of 'coming to know' and refers to children's active participation in their care. As well as the ways they received information about their care, the children also talked about how they were included in care decisions. The extents to which children were able to participate in this process were found to be variable, but according to the children, their inclusion was important and helped them to feel in control.

I: Does the doctor give you information about it?

C: Yeah kind of like what they're going to do and stuff

I: So you feel that you're given enough information that you need?

C: Yeah. Yeah (Boy, 10yrs).

In the current study, one area where children were often able to have some degree of choice at the time of their induction was whether they would have intravenous or gaseous induction of anaesthetic.

They had to give me the mask to help me go to sleep because

if I had a needle – sometimes I cry because I hate needles (Girl, 9yrs).

One child described in some detail the procedure for having an intravenous cannula inserted. He described the effect of the local anaesthetic cream applied to the area, the application of the tourniquet and its purpose. Although this child didn't like needles or cannulas and was frightened of this procedure, he also said that being provided with explanations about the procedure lessened the anxiety he felt:

C: It feels ... you can't feel very much only this [touching the back of his hand lightly] because they put this special ointment on you
I: When they were doing that did they tell you what they were going to do?
C: No. Yes... they have your arm out like that [straightening arm] and they put this thing around [circling upper arm with hand, indicating a tourniquet] that makes your veins show a bit more
I: So they explained that to you?
C: Yes
I: When they tell you what they are doing, what they are going to do, is that a good thing or a bad thing?
C: Good thing
I: And why is it good?
C: Because you don't worry when they put them in [the intravenous cannula] (Boy, 8yrs).

Information about the procedure resulted in the child having a sense of what was going to happen and therefore some sense of control.

One child had experienced post operative problems following discharge after tonsillectomy and adenoidectomy and refused to eat or drink. His concerned parents arranged for the child to be reviewed by their local general practitioner who told the mother that the parents would need to physically restrain the child to make him drink. Both child and mother talked to me (separately) about this experience and told me they were distressed by this advice. Because the child continued to refuse, he was seen by the specialist surgeon the next day. The surgeon spoke directly to the child and said to him that the child had a choice that he could either eat and drink, or be readmitted to hospital.

C: Cause when we saw a doctor on Monday, 'if you need to sit on him and shove it down his throat you do it'
I: Who said that?
C: A doctor down the road said that
I: ...So how did you feel about that?
C: Sad. Then we went to the doctor in town who done the operation
I: ... And what did that doctor say?
C: Um that I had to start eating [or go to hospital]
I: What did you decide?
C: To eat and drink (Boy, 7yrs).

The differences in the approaches of these two health care providers to this issue made a difference to the child's response and also to his wellbeing. Including the child in the decision making process, that is, by putting options directly to the child, resulted in the child deciding to eat and drink. This example demonstrates the

effectiveness of direct communication between medical staff and children and the resulting improvements in health care and satisfaction, compliance as well as better understanding.

Aside: The child's refusal to eat or drink following discharge was likely due to the pain he told me experienced when attempting to do so. This situation may have been the result of inadequate discharge information to both the child and parent about the importance of appropriate analgesia in the postoperative period.

The provision of information and appropriate explanations to children increased their sense of involvement and sense of control over what was happening to them, and facilitated their sense of self in this environment. Not being given information or being given conflicting information was not helpful to them. The following extract indicates the frustration and confusion that children can experience when given unclear or conflicting information about their condition and treatments, or when they are not provided with explanations:

I: So the ambulance brought you into hospital. Tell me what happened then

C: They took me out on a stretcher and I was sitting in a corridor for about 15 minutes and then they took me in a room and about 10 doctors would come in and ask the same questions over and over again

I: And how did you feel about that?

C: A bit annoying because I kept repeating myself and they would tell me it was appendix and then they tell me it wasn't appendix. It was frustrating and someone else would come in and say it was gastro and someone would tell me it wasn't

I: So there was some confusion there?

C: Yeah

I: And how did you feel about that?

C: Bit, like I didn't know what it was (Girl, 12yrs).

I: So after the operation on the ward here, what's it been like?

C: It's like...[pause] one person comes in and then they check my notes and everything and they um give me medicine and then another one comes in and says that you have to have the flush [a saline flush of the intravenous cannula for patency] you're due flush every 6 hours. And no-one come in and did it every 6 hours so she only did it once. Then they keep coming in and like all confusing because they were telling me all different things and doing all this other stuff and they weren't telling me why they were doing it

I: So what kind of things, what kind of times did that happen?

C: Most of the whole time I was in it

I: OK so you didn't get the information that you would have wanted?

C: Well they were doing it so if they flush it out they wouldn't get any infections and stuff in it. The others would just do things and just go 'they will be right' and everything and didn't tell me why they giving me stuff (Girl, 12yrs).

This child had been given to understand that her intravenous cannula needed to be flushed (with a saline solution to maintain patency) every six hours, and the reason for this was to prevent problems such as infection. Her experience was however, that the cannula was only flushed on one occasion, and this caused her concern. This child had just undergone surgery for an infected appendix and when her concern is considered in the context of her hospitalisation and surgery, we can understand the apprehension she felt. Misunderstandings can be harmless and without consequences, but they can add to the anxiety children experience in relation to the medical care they are provided (Gordon et al. 2002, p3).

Locating their selves

'Locating their selves' was a sub category of 'coming to know' and refers to the way the children made sense of their situation through situating themselves within the phenomenon. Children locate their sense of self in the familiar, the unknown of hospital and surgery therefore challenged the child's sense of self, their self image and self identity. This sense of unfamiliar and strangeness can be seen in the following quote:

C: Um, it felt real weird

I: Why was it weird?

C: Because I've never been in the hospital before and I've never had an operation (Girl, 9yrs).

It was apparent that the children moved through a process where initially they had little knowledge of what their surgery would entail and their illness and surgery presented a threat to their sense of self.

Illness, disease and surgery all impacted on the children's image of their body. This change in body image is seen in the drawing by one of the children below (Figure 9). In the drawing, the child represents herself in a wheelchair. Whilst this child would not normally need a wheelchair, during the period of recovery in hospital, she did occasionally use one for mobilising about the ward.



Figure 9: Drawing of child in a wheelchair (*Girl, 8 yrs*)

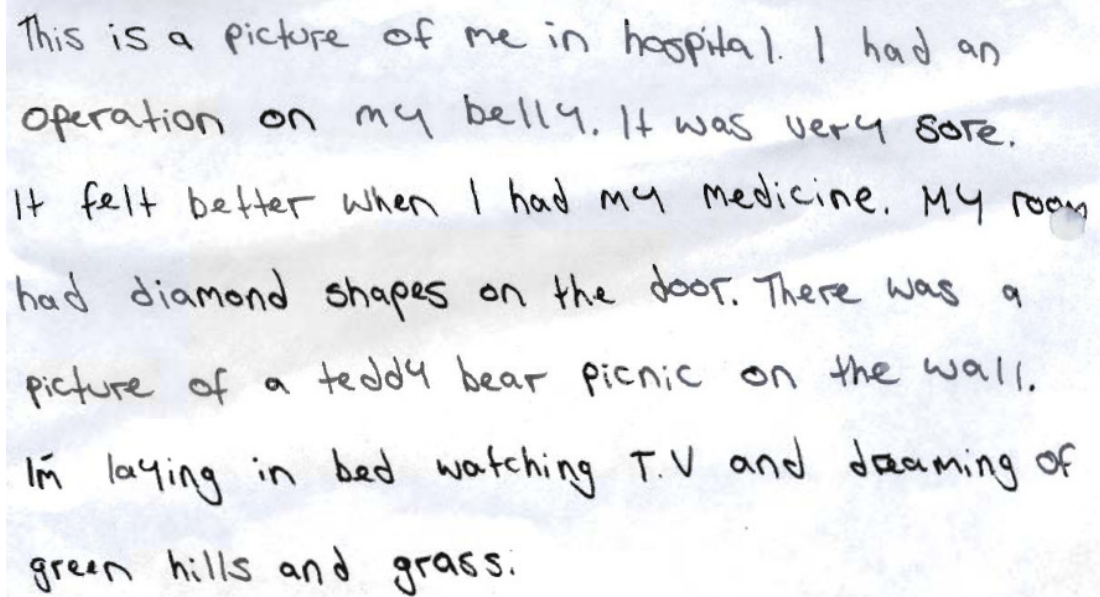
Developing a sense of place

Developing a sense of place refers to the place making activities the children were involved in and is linked to the sub category 'locating their selves'. Spaces usually occupied by children include the home, the school and neighbourhood. And children's sense of self is generally linked to their family, their friendships and their school. The hospital environment was not a part of the child's normal, every-day world. Hospital is not generally a space for children, and being hospitalised is not normally part of their sense of self. However, hospital becomes a lived place for the children admitted for surgery.

The following drawing (Figure 10) and the accompanying story by one child is her representation of the space she was in, and these provide further understanding about her perceptions of the setting.



Figure 10: Drawing of child in 'her' hospital room (Girl, 8 yrs)



This is a picture of me in hospital. I had an operation on my belly. It was very sore. It felt better when I had my medicine. My room had diamond shapes on the door. There was a picture of a teddy bear picnic on the wall. I'm laying in bed watching T.V and dreaming of green hills and grass.

This is a picture of me in hospital. I had an operation on my belly. It was very sore. It felt better when I had my medicine. My room had diamond shapes on the door. There was a picture of a teddy bear picnic on the wall. I'm laying in bed watching TV and dreaming of green hills and grass (Girl, 8yrs).

As well as describing her reason for being in hospital, she draws and writes about the physical environment. In the drawing the child depicts herself in the hospital setting – in this case the hospital room where she was cared for - and she refers to this room as her own ('my room'). She also draws and describes the child-friendly features of the room that include the shapes and colours of the door and the picture of 'the teddy bear's picnic' on the wall. The paediatric unit was seen to have a significant impact on the children's experience of admission for surgery.

The children's place-making activities around their experience of hospitalisation also included very familiar activities like watching television, playing games and attending 'school'. The findings of this research are consistent with other research that found that children try to find continuity between their hospital experience and their normal environment (Carney et al. 2003, p36). The current research demonstrated that relationships the children had with place (that is the hospital and the children's ward) influenced the way they positioned themselves and also the way they were positioned.

The familiar activities like school, reading, playing games and watching television were also identified as things the children liked about hospital. Drawings of their stay in hospital and their written and verbal comments included the children's views of the physical environment and things they saw and did whilst in the hospital. Their drawings included pictures of the hospital environment, of the hospital building; of the child in bed; or in a wheelchair; and medical equipment, specifically their intravenous infusion device.

The following is a drawing by one 6 year old child who was keen to do a drawing during the interview in hospital (Figure 11). This child had experienced a gangrenous appendix that required a period of intravenous antibiotics, and a relatively prolonged hospital stay of over a week. This child did not write text, but explained to me what the drawing was about. It was executed fairly quickly, and depicted the space he currently occupied, the room and bed. His ability to hold the felt pens was a little limited because he had a cannula in the back of his writing hand and he had an arm-board and bandage protecting the cannula.

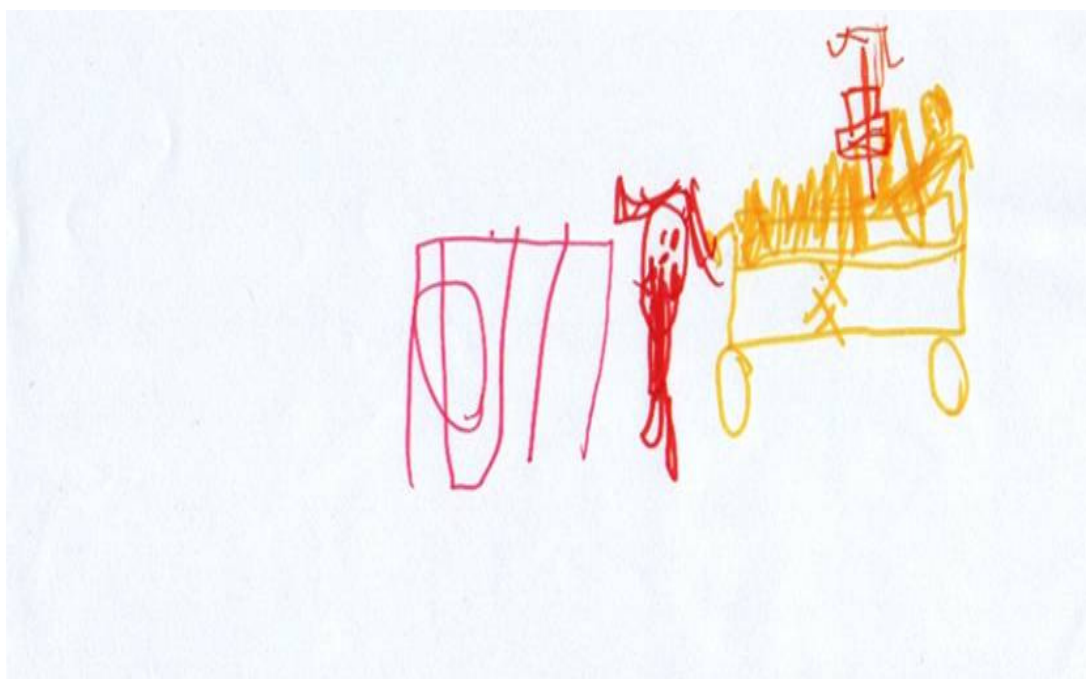


Figure 11: Drawing of child in a hospital bed (*Boy, 6 yrs*)

The child situated himself in the drawing (in the bed), and included detail of the bed. When he did this drawing, the child was in fact sitting in a chair beside the bed. Although difficult to identify in this image, the child is smiling. The child was receiving intravenous therapy during his admission and in the drawing he has included the drip stand, intravenous fluid and infusion pump. He included the door to the room and he told me the person at the foot of the bed is me (and I too am smiling). Drawing himself in the hospital room was one way of situating himself in that setting.

The next drawing by an 8 year old girl (Figure 12) is of the hospital building and was done 'carefully' in grey-lead pencil. The symbol of the red cross dominates the picture – although there is no red cross on the building. The stars in the picture represent the stars that form a trail on the ceiling from the children's ward to the operating suite. (The children are encouraged to follow the trail of stars when they are being transferred from the ward to the operating suite). The child also included in the drawing a tulip – her father grows tulips in their garden at home.



Figure 12: Drawing of hospital (Girl, 8 yrs)

The child has incorporated familiar images, that is, the flower from her garden and the red cross, in her drawing of the less familiar hospital. The red cross is a symbol the child has learned to associate with hospitals through her life experiences. Through the drawing, the child is engaged in making meanings of her situation and so the link to symbolic interactionism is evident.

The children's development of a sense of place was an essential part of the process of making sense of their experience of hospitalisation for surgery. Whilst the information sources discussed in this section were important ways the children developed understanding, their limited experience or knowledge of hospitals and surgery impacted on them and strategies were needed to assist them in the meaning making processes. The organising of events and the development of scripts and schemas was part of that process.

Organising accounts of events

Children's organising accounts of events is linked to the sub category 'locating their selves'. In order to assist them in gaining an understanding and a sense of place, children described their physical movements through the hospital. The following quote describes one child's journey from home to hospital and from the Emergency Department to the room he would occupy in the children's ward:

C: Yes and dad drove me there. And um, we had to wait in the waiting room for a very long time

I: It was a long time was it?

C: Mmm...

I: So you were waiting in the waiting room for a long time, then what happened?

C: They called my name and then they put me on to a bed. Then they pushed me into a room. Then they took me out of the room after a little while. And then they um,... Then I went into a lift, then they went down this big long, twirly corridor sort of thing.,

I: Where did you go then?

C: I went into a little room. And (pause)

I: And then what happened?

C: And then I went to sleep (Boy, 6yrs).

In addition to organising events in terms of their physical location, children did this through reference to time, and this is evidenced in the following excerpt from a story written by one of the children:

me the same questions. then ~~after~~ ^{at} two o'clock a nurse came in and took a blood test and put a needle in she said it was for my drip then at nine thirty at night they took me in for my operation and my dad came in with me but he had to go as soon as I went to sleep. When I woke up it was eleven o'clock. My mom and my dad and my brother were there. They talked to me for a while and then the sergeants [meaning orderlies] moved me into a room and then I went straight to sleep.

Then at two o'clock a nurse came in and took a blood test and put a needle in. She said it was for my drip. Then at nine thirty at night they took me in for my operation and my dad came in with me but he had to go as soon as I went to sleep. When I woke up it was eleven o'clock. My mom and my dad and my brother were there. They talked to me for a while and then the sergeants [meaning orderlies] moved me into a room and then I went straight to sleep. (Girl, 12yrs).

The next quote is from a child who has experienced several intravenous cannulations for the administration of anaesthetic. He talked about how a doctor had provided him with explanations about the procedure. He was able to predict how the procedure was performed, and therefore (although he still did not like the idea of the procedure) was better able to cope:

It feels ... you can't feel very much only this [touching the back of his hand lightly] because they put this special ointment on you... they have your arm out like that [straightening arm] and they put this thing around [circling upper arm with hand, indicating a tourniquet] that makes your veins show a bit more (Boy, 8yrs).

The sequencing of events by children in order to make sense of their hospitalisation has also been described in the literature (Carney et al. 2003). By using the impersonal pronoun (you) and the timeless present tense, children organise an event as a set of expectations that the event will be structured in a similar way (Hudson et al. 1992). A number of children gave organised accounts of events, using 'you' and the present tense. The previous quote about insertion of the cannula and the following excerpts are examples of this. Here two children explained the process for induction of anaesthetic:

Well they give you the pain killers and stuff and before you - they put you to sleep they put this numbing cream on so the needle doesn't hurt at all (Boy, 10yrs).

No because this one they put this drip in and then it only ever went through, through with this needle and they put the needle in with a tube on top of it and they just slide the needle out and the tube's still in there and then they put this medicine and they put it in there and that's how.. and it stings you for a second and you just fall asleep.(Boy, 8yrs).

Children who were admitted to hospital for surgery acted on the basis of the meaning this situation had for them. One child talked about the 'routine' he had developed with his mother when undergoing induction of anaesthetic.

I: And what were you thinking when you went to sleep?

C: I try to count sometimes

Mother: You say bye bye to me, don't you?

C: Love you mummy bye bye, and then you're asleep (Boy, 8yrs).

The mother would be with her child at induction of anaesthetic. As he went to sleep he would say 'Love you mummy, bye bye', he would then go to sleep and he understood that his mother would be there for him soon after he woke from his operation.

In summary, one of the processes children were engaged in, as they moved through the experience of admission to hospital for surgery, was that of 'coming to know'. 'Coming to know' incorporated the children's developing understandings, their participation in care decisions and locating their selves within the situation.

Bouncing back

The next concept, and the second basic social process was identified as 'bouncing back'. The concept 'bouncing back' refers to how children were able to successfully deal with their illness, hospitalisation and surgery and move on from these and get on with their normal lives. It incorporates the sub categories 'optimism' and 'coping with pain'.

'Bouncing back' demonstrates how the children drew on a number of coping skills in order to move past the adversity that hospitalisation and surgery presented, including their experience of illness and pain, and by so doing the children demonstrated

resilience. Their resilience and ways of coping were important features of the children's experience, as has been mentioned in several points in the previous chapter. 'Bouncing back' represents the outcome or consequence of the children's resilience and coping.

Optimism

'Optimism' is a sub category of the concept 'bouncing back' and refers to the way children viewed their situation in a positive light. A number of children expressed positive feelings about going to hospital because they were feeling sick or unwell and they wanted to feel better, and they understood their surgery would 'make them better.'

I: What did you think about that [the operation]

C: Good

I: You thought it was good. Because why?

C: Um getting my tonsils out cause they are all sore (Boy, 7yrs).

I: And when mum said we better go to hospital what did you feel?

What did you think of that?

C: I was happy and scared

I: Why were you happy?

C: Um just to get - to have an operation to get well and things like that (Girl, 8yrs).

Following their discharge from hospital, children indicated that they had 'moved on' from the experience. For example, when one child was asked what he thought about the scar from his appendicectomy, he said he didn't think about it:

I: What do you think about it [his scar]?

C: ...mmm - I don't really think about it (Boy, 6yrs).

He was asked this question in an interview at his home after his discharge. He felt well and was not bothered at all by after effects from his surgery. Another child was quite proud of her appendicectomy scar:

I: So what do you think about it [her scar]?

C: Pretty cool (Girl, 8yrs).

Her scar was something like a badge, she thought it was cool and had happily showed it to me when she described her surgery in the same interview. Surprisingly, one child talked as though she had forgotten that she had surgery:

You don't... when I came out of hospital I didn't know that I had it out... And I forgot all the things how like hard [it was to take] the medicine... I said 'whose medicine is that' she said its all yours for your tonsils, And I go I never had my tonsils out. I forgot all about it! (Girl, 9yrs).

This child had a secondary bleed after discharge following tonsillectomy and adenoidectomy that required her to represent to the Emergency Department. This experience was understandably somewhat traumatic for her, as she explained:

*C: Well I cried a bit but mum wanted to get me in hospital
Because I was bleeding from my nose and mouth and it kept on coming out -
it was all over my face and body and stuff and my pyjamas...
I: And what happened then?
C: They were going to let me sleep in but they had no beds
I: So did it stop bleeding then?
C: Well it kept on going a little bit and they said when I sleep some blood
comes well I will cough and wake up but I didn't at all
I: So what was that like?
C: It was really bad
I: Why was it bad?
C: Because I really hate blood because if I see it, I cry because I don't like
blood at all, I never have (Girl, 9yrs).*

Although her experience was difficult, she demonstrated that she had been able to 'move on' from this further adversity. She was able to talk openly about her experience to me in our interviews and she also talked about her experience of talking to her friends at school where she was a centre of attention and subject to the praise of her peers (refer to p174). The ways that these children talked about their experiences provides an indication that these children had moved on from their experience.

Coping with pain

'Coping with pain' was a sub category of the concept 'bouncing back' and refers to the ways that children interacted and coped with their own pain. The children utilised and drew upon a wide range of strategies for dealing with their pain. These included pharmacological as well as non-pharmacological strategies such as analgesic preparations; limiting activity by lying still, resting and sleeping; cognitive and visual distraction; physical comforting techniques such as touch/massage and drawing upon social support strategies, particularly parents.

In the following extracts the children describe their use of these different techniques for minimising or dealing with their pain:

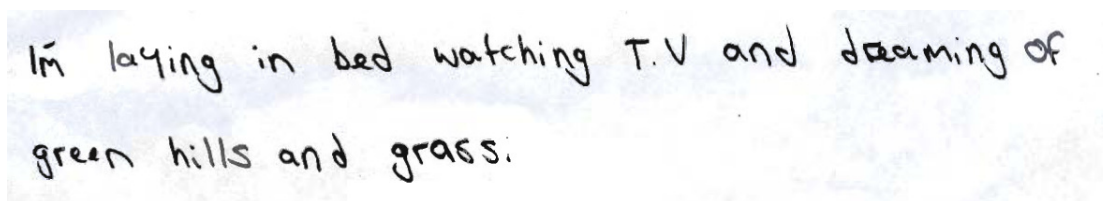
I: What did you do about that?
C: I tried to keep still and then it wasn't sore
I: ... what else might you do?
C: Pink stuff (Medicine)
I: ... And how does it make you feel?
C: Umm doesn't... it sort of takes away the pain (Boy, 8yrs).

C: Most of the time I watched tv
I: Why did you watch tv?
C: Because I couldn't do very much
I: Why couldn't you do very much?
C: Because my tummy was hurting still
I: ... what did you do about the hurting? Tell me about that.
C: I had to take yucky medicine that made me vomit (Girl, 8yrs).

Mother: She was very sick yesterday though weren't you?
C: All I wanted to do was sleep (Girl, 9yrs).

In this last quote, sleeping was a response the child used to deal with her pain. The need or desire for sleep could be linked to the illness/recovery state and as well as the effect of the analgesia she received. Sleep has also been identified as a coping strategy that children utilise where they deliberately seek to keep away from a stressor. Sleep in that instance is used as a behaviour avoidance mechanism and presents an activity the child can use to maintain a level of control in an environment where they typically have little control (Board 2005, p173). For the children in this study, the role of sleep may have been all of these things.

One child's drawings and associated story indicated the distraction techniques she utilised to deal with her postoperative pain.



I'm laying in bed watching T.V and dreaming of
green hills and grass.

I'm laying in bed watching T.V and dreaming of green hills and grass (Girl, 8yrs).

This child's use of distraction was a form of coping that served to empower her and to turn the negative experience of pain around. It is one example of how the children described themselves as central figures in managing or coping with the pain they experienced. The children described behaviours or actions that they themselves initiated to deal with the pain and to provide some relief from the pain. That children viewed themselves as being active agents in their pain management has also been described in other studies with children (Franck et al. 2008, Woodgate and Kristjanson 1996a).

In addition to their own internal coping features, it was evident that the children had a strong reliance upon the care provided by others, particularly their parents in providing physical support and presence to help them with their pain. This is evidenced in the following quote, that also indicates how this child used touch as a way of managing her pain:

I: We just talked about the medicine and [how] it didn't take all the pain away

C: Mmm. it didn't exactly take it all away, but it still hurt.

I: So what did you do about that when you were sore?

C: I just rubbed it, and lied down on my mum (Girl, 8yrs).

The social support systems the children relied upon was identified as a significant feature of the context of their situation, described as 'being held' discussed in the next section.

In summary, children's admission to hospital for surgery presented a form of adversity for them. Children participating in the research demonstrated the ability for 'bouncing back' - moving on with life and getting back to normal following their admission, illness condition and surgery. Their attachments to the significant adults in their lives (their parents), their adaptability and humour were also qualities that were demonstrated as part of the process of 'bouncing back'.

Being held

The concept 'being held' refers to the children's sense of being cared for. The children's need for the support of those caring for them, both parents and staff, at this time was of major importance and had a strong influence on their sense of being cared for. The concept 'being held' included the sub categories of 'parents as primary care givers'; 'the caring role of nurses and doctors'; and 'a child friendly environment'.

Children require social and emotional support to cope with the challenges of daily life, and as has been indicated, these needs were increased during their hospitalisation for surgery. The socio-cultural context that included effective supports played a crucial role in the successful coping of children, and had a buffering effect in dealing with the stress they experienced as a result of the admission and surgery. In addition, a child friendly environment that was conducive and supportive of the children's well-being was important.

It was clear that from the children's perspectives, the main support and facilitating process for the children was their reliance on their parents and family. It is also clear that these important and previously established relationships retained their central role for the children throughout their hospitalisation. Their relationships with their parents and families were described by the children as essential, particularly in the most critical times of their admission. Children's positive interactions with health care providers - nurses and doctors as well as with play leaders, hospital clowns, other staff were also found to have a beneficial influence on the children's experience, as did the activities that children found enjoyable during their hospitalisation.

Parents as primary care givers

'Parents as primary caregivers' was a sub category of 'being held'. This sub category refers to the central role parents had in caring for the children, from the perspective of the children. Parents and family members were identified by the children to be primary care providers during the children's hospitalisation. Health care providers, including both doctors and nurses were identified as people who had a secondary role and who cared for the children in the absence of their parents.

I: Who's been looking after you?

C: My mum... and nurses and doctors (Girl, 8yrs).

I: Mum's going to help look after you. Who else is going to look after you?

C: Dad

I: Yes and is there anyone else who'll look after you when you are in hospital?

C: Yeah, and I think pop (Boy, 7yrs).

In all of the interviews with children, the central place of their families in their lives, and the children's reliance on their families whilst in hospital was clearly articulated. In the following quote, it is apparent that for this for child, one of her parents needed to be with her at all times. Her parents effectively 'took turns' to be with her throughout her time in hospital:

That mum and dad had to stay with me, that one of them had to stay with me (Girl, 8yrs).

Children in this study relied on their parents being with them and indeed, their parent's presence was essential to their wellbeing. The children said their parents looked after their general care needs because they were unwell, and that they also needed their parents' presence and support because of their fears and anxieties. Their parent's presence helped in reducing the levels of anxiety they experienced because of their illness, hospitalisation and treatments; and also that their parent's presence helped in preventing them from feeling frightened about some aspects of their situation. For example, one girl described how important it was for her mother to be present at night because of her fear of the dark:

C: Yes because she's [mother] been staying the night and stuff with me

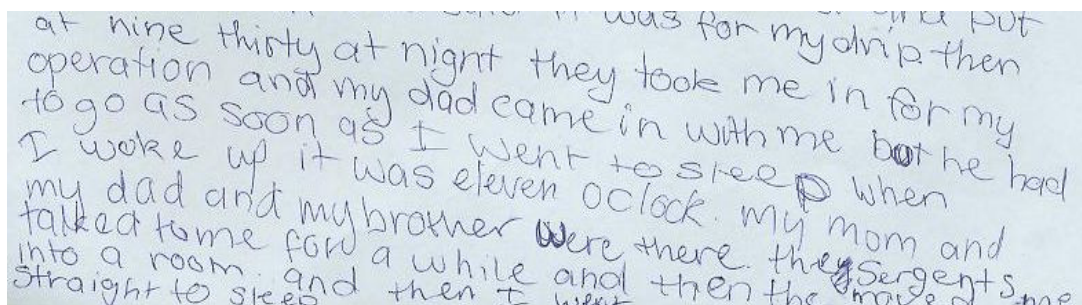
I: And [why] was that important?

C: Because if she wasn't here I would be really scared and would wake up in the night and be really scared cause I'm scared of the dark (Girl, 8yrs).

The importance of the parent's presence at critical times such as the time of anaesthetic induction, as has been discussed (refer to p159) was also clearly articulated by the children.

The children talked about both their mothers and fathers having important roles in being with the children. Fathers as well as mothers stayed with the child, sometimes either the father or the mother would be present throughout the hospital stay, and at

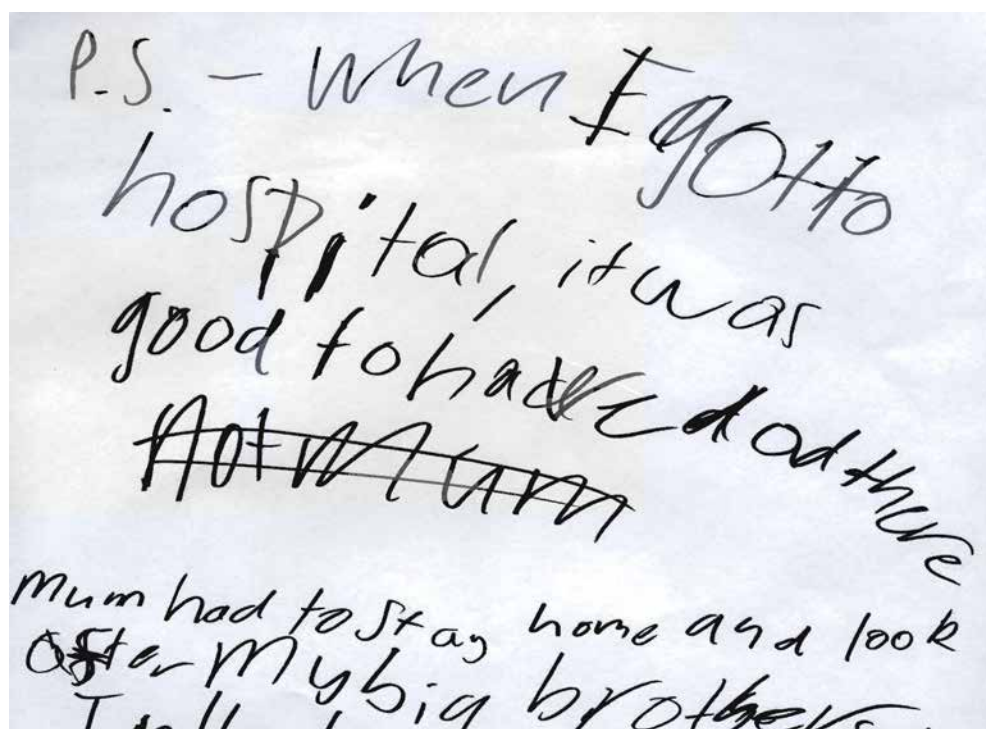
other times parental presence was shared between them. In the following excerpt, the child talks about how both her parents (who were separated) were present around the time of her surgery:



at nine thirty at night they took me in for my operation and my dad came in with me but he had to go as soon as I went to sleep. When I woke up it was eleven o'clock. My mom and my dad and my brother were there. They talked to me for a while and then they moved me into a room and then I went straight to sleep.

At nine thirty at night they took me in for my operation and my dad came in with me but he had to go as soon as I went to sleep. When I woke up it was eleven o'clock. My mum and my dad and my brother were there. They talked to me for a while...(Girl, 12yrs).

In the following excerpt, the boy, who was from another area of the state, describes how it was good to have his father with him during his time in hospital, while his mother cared for his brother at home.



P.S. - When I got to hospital, it was good to have dad there ~~not mum~~. Mum had to stay home and look after my big brother.

P.S. - when I got to hospital, it was good to have dad there (not mum) Mum had to stay home and look after my big brother (Boy, 11yrs).

The literature around children's hospitalisation and family support has mainly focused on mother's roles, with less attention on whole families (Hopia et al. 2005, p213). This might be due to current pattern of childcare where mothers remain the predominant child carers (Darbyshire 2003, p294). In this study, the children identified that both parents played active and important roles, as did grandparents and even extended family – cousins, aunts and uncles.

The caring role of nurses and doctors

'The caring role of nurses and doctors' was a sub category of 'being held' and refers to the support provided by these people within this setting that supplemented and complemented the support of the child's parents, family and friends. Whilst the children viewed their parents as their primary carers, they generally viewed the role of nurses and doctors to also be a caring one, where they provided assistance to the child and helped the child in their recovery. The children's comments indicate their understandings of nurses' roles were in relation to providing emotional and physical care as well as treatments such as medication administration. These following excerpts were the responses to questions about the role of nurses. Although the focus of the questions I asked was particularly in relation to nurses and their role, the children often combined nurses and doctors together in their responses:

I: What did the nurses do when you were in hospital?

C: They give .. I have to press this button and one of the nurse and doctor always came to me

I: And what kind of things did they do for you?

C: Um they gave me medicine and um... something to eat (Girl, 11yrs).

C: They gave me needles and medicine

I: Yeah and what other things did they do?

C: Umm.. they fixed me up

I: And how did they do that?

C: Um.. they gave me an operation (Girl, 8yrs).

The child said that the nurse (and doctor) 'always came' when she pressed the call bell and this would indicate the level of trust the child had that this would be the case.

The children described some of the qualities of nurses and doctors:

I: Can you tell me what are some of the good things about being in hospital?

C: Because the doctors and nurses help you get better and stuff (Girl, 8yrs).

I: So can you tell me what the nurses did when you were in hospital?

C: They were nice (Boy, 7yrs).

I: What would you tell them (other children who needed to go to hospital) about the doctors and the nurses?

C: That they're very kind and helpful (Girl, 8yrs).

I: Can you tell me what they did?

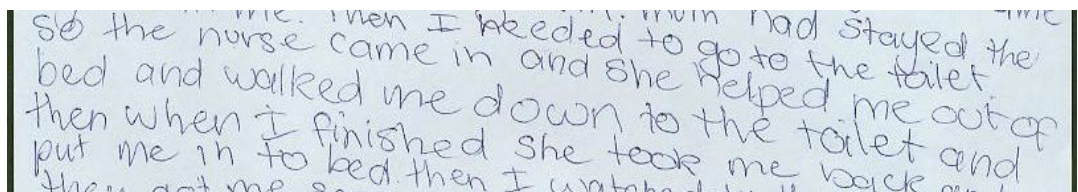
C: Well they check on you like every night and every hour or so and stuff and they really help you get better

I: How do they do that?

C: Well they give you medicine to make you feel better and stuff (Girl, 9yrs).

They give you this.. they .. they make you feel better you got to stay in hospital until you feel better (Girl, 9yrs).

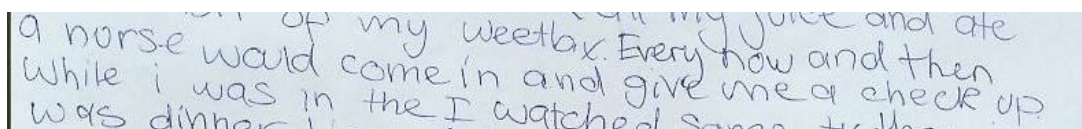
The role of assisting children with toileting and dressing was also described by the children:



So the nurse came in and she helped me out of bed and walked me down to the toilet and put me in to bed then she took me back and then I watched her back

So the nurse came in and she helped me out of bed and walked me down to the toilet and put me in bed (Girl, 12yrs).

The monitoring role of nurses to ensure the child's wellbeing was described, as instanced above by the child who said 'they check on you' and in the following quote:



a nurse would come in and give me a check up while I was in the I watched some of the

Every now and then a nurse would come in and give me a check up (Girl, 12yrs).

The fun aspect of the nurse's role as described by the children was presented in the previous chapter under the concept of having fun. This part of the children's interactions with nurses was seen to have a positive impact on their experience.

Nurses' humanity was the most valued personal attribute for the children participating in research by Pelander and Leino-Kilpi (2004). The expectations of children in their study were for nurses to be 'nice', 'kind' and 'helpful' and to have a sense of humour. Nurses in that study were also expected to provide physical care and treatment. Children emphasised the impact that communication and relationships with staff have on their experience of healthcare in research by Curtis et al (2004). The children in the study reported the importance to them of direct communication; sensitivity and even small acts of consideration were appreciated by the children. The research also showed that when communication and relationships were not effective that children expressed most concerns (p152). Research by Randall (2008) with hospitalised children found that the ability to have fun was an essential characteristic of 'good children's nurses' identified by the children (p24).

A study by McDonald and Rushforth (2006) explored children's views of nursing and medical roles and found that children attributed nurses with roles around 'caring', 'giving medicines', 'playing', 'taking temperatures' and 'making people better'. The study also found children attributed doctors roles as performing surgery, 'making people better', 'listening to hearts and chests' and 'giving medicine' (p34).

In this current research, as has been demonstrated in the previous quotes, children often spoke of 'doctors and nurses' together, and they sometimes found it difficult to differentiate the role of the doctor and the nurse. Role confusion has also been a finding in other studies (McDonald and Rushforth 2006). This confusion around the differentiation of the doctors and nurses roles may be in part because of the dress of the medical and nursing staff. In the perioperative areas for example, all staff wear blue 'scrubs'. In the ward areas, staff do not wear traditional uniforms.

Perhaps this 'role confusion' may also be because staff do not clearly introduce themselves to the children, including an explanation of their roles. The children talked of meeting a large number of new and different people during their hospitalisation. However, for the children, being able to name the people caring for them had importance. When the children knew the name of their nurse, the children referred to them by name in the interviews. In a written piece, one boy described the recovery nurse who cared for him:

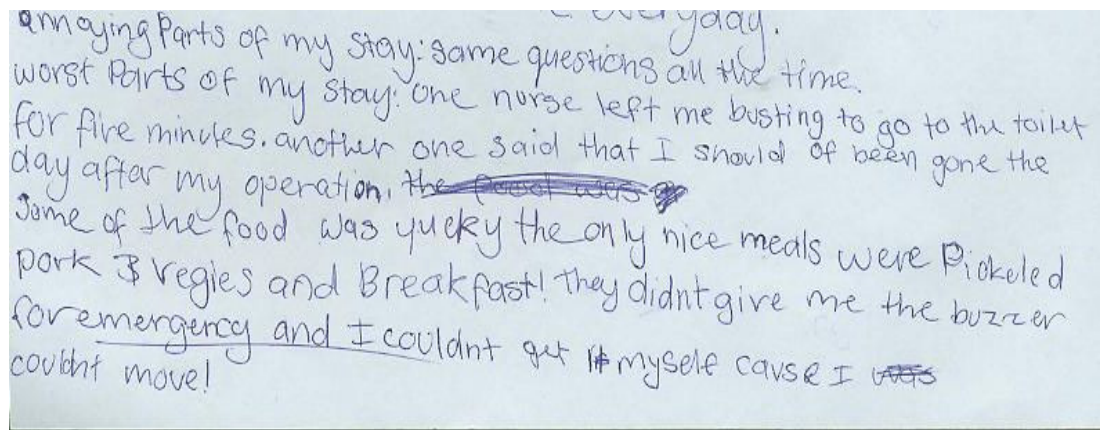
This is [name]. She works in recovery. She makes me laugh and makes my mum laugh, and I think she's great (Boy, 8yrs).

They also indicated when this was not the case:

Um,.. the I can't really remember their names (Girl, 8yrs).

In this study, the majority of the children's descriptions of nurses and doctors were positive ones, as children described their role to assist in the children's recovery.

However, this was not always the case. Children also experienced less positive interactions, and one girl wrote of these:



The image shows a piece of paper with handwritten text in blue ink. The text is written in a cursive, child-like script. It describes various annoyances and negative experiences during a hospital stay, including repetitive questions, a nurse leaving the child in a vulnerable position, a comment about being discharged, and dissatisfaction with the food and emergency procedures.

annoying parts of my stay: same questions all the time.
worst parts of my stay: one nurse left me busting to go to the toilet
for five minutes. another one said that I should of been gone the
day after my operation. ~~the food was~~
some of the food was yucky the only nice meals were Pickled
pork & vegies and Breakfast! They didnt give me the buzzer
for emergency and I couldnt get it myself cause I ~~was~~
couldnt move!

Annoying parts of my stay: same questions all the time.

Worst parts of my stay: One nurse left me busting to go to the toilet for five minutes. Another one said that I should of been gone the day after my operation.

Some of the food was yucky the only nice meals were pickled pork & vegies and breakfast! They didn't give me the buzzer for emergency and I couldn't get it myself cause I couldn't move! (Girl, 12yrs).

The comment by the nurse that the child should have been discharged already made the child feel unwelcome. This girl's comment that the buzzer (the call bell) was out of reach contrasts to the previous comment that indicated the trust another child had that a nurse would always come if the child rang the bell. In this instance, not having access to the call bell and being left to wait by a nurse to go to the toilet made the child feel helpless and vulnerable and increased her sense of feeling unsafe.

The literature reports unaccompanied children struggling to get the attention of nurses, for example, when they need to go to the toilet (Livesley 2005, p44). The child above described having to wait and to go to the toilet as one of the worst things

about her stay in hospital. The distress such instances cause children is significant and memories of such events can stay with them.

In this section, the important role of parents and the role of nurses in relation to the context of 'being held' have been discussed. This next section outlines other aspects of the environment, both social and physical, that were part of the children's experience and that were an essential part of their 'being held'.

A child friendly environment

'A child friendly environment' was a sub category of 'being held' and refers to the supportive environment required for children admitted to hospital. A supportive, child friendly environment was an integral part of the context required for the children to feel 'held' and this environment had both social and physical aspects. In Chapter 6, the social activities the children enjoyed whilst in hospital were identified (under the concept 'having fun') and these included visits from family and friends; their fun and humorous interactions with others; as well as being able to participate in schooling and different play activities. Children enjoyed the opportunity to engage in familiar activities and the provision for children in hospital to continue their familiar routines is a recommendation of the Child Friendly Healthcare Initiative (Nicholson and Clarke 2007, p49).

As well as social aspects, the children identified some of the child-friendly aspects of the children's ward that related to the physical environment. One child described the physical aspects thus:

I: So what did you think of the children's ward?

C: It felt.. it was really nice... The way they painted it and stuff and like how they had a baby's room with it and all. And they had real nice colours. The way they had it inside and out the front and it shows you what number you're in (Girl, 9yrs).

The child-friendly aspects of the paediatric unit, such as the colours and the pictures had a positive impact on the children. For instance, the child's quote above also makes reference to brightly coloured murals at the entrance to the paediatric unit. The murals provide children with a welcome to the unit. Other children made reference to the stars that line the ceiling from the ward to the operating rooms, depicted in an earlier drawing (Figure 12) and again here (Figure 13):

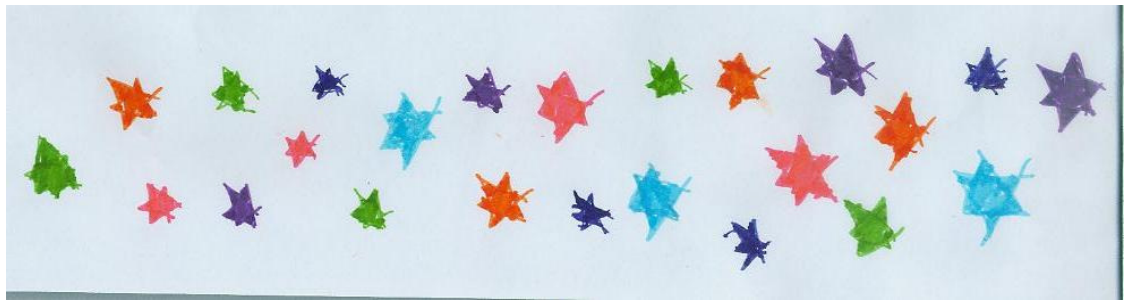


Figure 13: Drawing of stars on the ceiling (Boy, 8 yrs)

In keeping with recommendations for children's hospital care (RACP 2008), the unit whenever possible has separate areas for caring for children of different ages, but this is not always the case. The child's quote above for instance - '*they had a baby's room*' – refers to the nursery area in the ward.

Key environmental features that have been found to support children's hospital experience include: age appropriate activities and spaces; access to school; a need for privacy and community; the importance of bright colours, soft furnishings and age-appropriate art work (Bishop 2008, p35). Research also shows that a welcoming, stimulating, pleasant environment that provides opportunities to play and learn contributes to both children's recovery from illness and their development (Nicholson and Clarke 2007, p49). Long corridors, waiting areas and treatment rooms can all be frightening for children and attempts to make them child friendly in appearance (such as the murals and the stars) can reduce children's anxiety and fear (Nicholson and Clarke 2007, p49). Whilst the children participating in this study did not have access to outdoor play facilities, access to such facilities is a recommendation for hospitalised children (AWCH 2002, p2).

The socio-cultural context of children's hospitalisation clearly had an impact on their experience. The child is a part of social and environmental relationships and children who are admitted to hospital are impacted on, as well as impact this setting. Their interactions with the physical environment and the people within that environment influenced their experience. For paediatric hospital settings to be more child-friendly in both appearances and in practices reflects the social and political calls for services to meet the needs of children.

Conclusion

These 2 chapters of the thesis present the findings from the research exploring the experience of children who are admitted to hospital for surgery from their perspective, and specifically address the contexts, meanings and processes of this studied phenomenon. The children engaged in active meaning making to make sense of the unfamiliar experience hospitalisation presented. 'Coming to know' represented how the children moved through the experience and how they grappled with making sense of it. Children drew on a number of coping skills to move past the adversity of hospitalisation and surgery and when they achieved this, they were able to 'bounce back' and move on from the experience. A facilitating, supportive environment was the required context, described from the child's perspective as 'being held'.

The next chapter builds on these findings and presents the interpretive and theoretical renderings that gave rise to a substantive theory of primary school age children's admission to hospital for surgery.

Chapter 8: A theory of primary school age children's admission to hospital for surgery

The grounded theorist's analysis tells a story about people, social processes, and situations. The researcher composes the story; it does not simply unfold before the eyes of an objective viewer. The story reflects the viewer as well as the viewed (Charmaz 2000, p522).

The focus of this chapter is the interpretation and theoretical renderings of findings from the previous two chapters. This is in order to meet the aim of the research: to explore children's admission to hospital for surgery from the perspective of children and so develop a substantive theory that provides increased understanding of this phenomenon. Following a constructivist grounded theory approach, the discussion is a synthesis of the research findings, with relevant literature and my own interpretive perspectives, and reflects the quote above. This part of the work also acknowledges prior theoretical works; locates this study within the relevant discourses; and positions the new substantive theory in relation to those theories - thereby showing where the work fits or extends relevant literatures and theories (Charmaz 2006, p169).

A constructivist grounded theory approach has provided the conceptual framework for this study resulting in increased understandings of children's admission for surgery from as close to the children's perspective as possible. This work has revealed the meanings, processes and contexts for the studied phenomenon of children's admission for surgery and resulted in the theorising of this phenomenon. The theory is based on analysis and interpretations of children's descriptions of what that experience was for them, and how they experienced the phenomenon and the meanings that they made around the experience. The processes included the ways that they came to know or understand the experience that was generally outside of their normal world and how they were able to incorporate the experience into their sense of self. The context was the environment that consisted of both physical and social aspects.

A substantive theory of primary school age children's admission to hospital for surgery, from their perspective, has been developed from this constructivist grounded

theory study. The substantive theory is encapsulated in the textbox below and then further expanded in the following pages.

A theory of children's reframing their sense of self to incorporate the experience of admission to hospital for surgery

Primary school age children's admission to hospital for surgery presents a form of adversity for them that they experience as an embodied experience of contrasts. Their illness and surgery presents a challenge to children and impacts on their sense of self and the ways they view their bodies. Children engage in active meaning making in order to successfully assimilate and accommodate the experience of admission to hospital and surgery into their sense of self. Over time and with experience, children are able to reframe their sense of self to incorporate these experiences. Children draw on innate coping systems, and the provision of a facilitating, holding environment to successfully reintegrate this experience of adversity. When children do achieve reintegration they are able to move on from the adversity, or bounce back.

The discussion is presented under the major headings identified in the previous chapters: the phenomenon, the processes and the context. By using a conceptual bridge of this kind, the connections that are present within and between concepts, and that are an inherent part of the analytic process in grounded theory, are made clear (Charmaz 2006, p159).

The phenomenon – an embodied experience of contrasts

The studied phenomenon of this research was children's admission to hospital for surgery, from their perspective. Analysis of the data revealed that admission to hospital was not a part of the children's normal world, and presented a form of adversity for them. In addition, their admission to hospital and surgery had a strong impact on the children and the way they experienced their bodies and viewed their sense of self.

Children experienced admission to hospital for surgery as an embodied experience of contrasts that involved the children's whole being and that incorporated physical, emotional and psychosocial aspects of the child's self. This view links to the view of the body within social theory, where the body is considered as multidimensional, comprised of the physical body, the mind and emotions.

From the sociological perspective, children are recognised as being actively engaged in their own embodied experience (Rees and Pithouse 2008, p338). The linked status of children's bodies and children's minds and the linkages between 'the bodily and the cognitive' (Mayall 1996, p4) are important constructs in this work. The children's physical, emotional and psychosocial experiences of the phenomenon were interactive and essentially linked, for '[c]hildren experience and interpret the world in ways that are inherently embodied' (Rogers et al. 2005, p162). How and what the children perceived during their experience of admission and surgery depended upon their bodily states and feelings. This extended to how they used language, constructed memories, and how they made meanings of being situated in the experience (Rogers et al. 2005, p162).

For example, children learned to use new language in response to their illness. The learning of a new word such as 'appendicitis' was accompanied by the understandings about just what '*appendicitis*' meant for *them*. These understandings were gained over time, and within their experience, that again had physical, emotional and psychosocial connotations. In relation to pain, the children described their thoughts and feelings about experiences of feeling physical pain and their associated emotional and psychosocial responses. They spoke of the physical nature of their pain, and the physical limitations pain imposed on them, such as being confined to bed. They described the emotional effects pain had and the supports they drew on to help them cope with their pain, for example, their need for their parents to provide both physical and emotional care.

Their memories were impacted by their physical condition, and their interactions with others, as well as the things they saw and heard. The strange people, sights and sounds of hospital was a cause of anxiety for them and the familiar people, sights and sounds provided them with reassurance. One girl, crying and frightened on her

transfer to theatre had positive memories of her interactions with staff who provided her with emotional support.

Children in this study experienced pain, illness and surgery, and so became very aware of their physical bodies, and they also became aware of the threats these things posed to their bodies. Recall the quote from Alderson (1993, p179) about the threat cannulation presents to a child's sense of self (p164 in this work). An individual's relationship to their body is generally taken-for-granted. Normally, the body tends to 'recede from view', and it is only when resistances, such as pain or illness, are encountered, do they re-appear or *dys*-appear (Williams and Bendelow 1998, p119). Hospital and healthcare focuses particularly on the physical body, often neglecting the cognitive and emotional aspects of the person. But these aspects are not discrete (Mayall 1996, p109). According to Benner (2000, p6), illness disrupts the person's embodied access to the world and medical language is silent about the human experience of illness, recovery and health. This view also follows the distinction made by Merleau-Ponty between the 'body object', that is the body of medicine, and the 'lived body' or 'body subject', the body of personal experience – that is of particular relevance in nursing (Thomas 2005, p71). The aim of this grounded theory study was to explore the phenomenon as experienced by children and so the study focuses on the body of personal experience - the 'lived body' or 'body subject'.

The children's experience, or their embodied agency, within the hospital setting was impacted by the fact that admission to hospital was not a part of the children's normal world, as is the home and school that are social contexts for children's daily lives. The children were required to engage with the highly complex environment of hospital in physical, emotional and psychosocial ways. Further, children who are admitted to hospital are required to subjugate their bodies to others: they undergo invasive and painful treatments and procedures, and for the children in this study, surgery. In addition, the children were required to learn the norms of social behaviour within the hospital, reflecting the socially constructed space where they had little or no control.

The uncertainty experienced by the children impacted on their sense of self and influenced the ways they adapted and coped with their situation. Conceptions of self are defined by Corbin and Strauss (1987) as '...not merely self-esteem but the views

held of oneself, in relation to the whole of identity – who I am’ (p245-255). Their experiences threatened the children’s sense of self, and illness and surgery have been recognised as threats to a person’s sense of integrity of *self and the body* and of *self and the world* (Charmaz 2006, p 170). In relation to their hospitalisation and surgery, the embodied experience as described by the children was influenced by past experiences and meanings as well as their interactions whilst within the experience. The influence of the past as well as the interactions within the situation is consistent with a symbolic interactionist perspective.

The body has been described as the means through which individuals are attached to, or ruptured from society. Studies on the construction of the self and experiences of illness have highlighted the importance of the uncertain impact of disease; the implications of disease trajectory (particularly in respect to chronic illness); and how individuals adapt and cope with illness (Charmaz 2006, Charmaz 2009). Further, responses to illness are considered to be shaped by the social and cultural context of the individual – that is their biography – which incorporates physical, social and existential dimensions (Hinsley and Hughes 2007, p84).

In 1996, Mayall claimed that children had largely been excluded from consideration of embodiment in the literature (p3). One of the few works since that time that discusses children’s embodiment in relation to healthcare is research by Williams and Bendelow (1998, 2000). Well children were the participants in their study that explored children’s perceptions of cancer. This current research differs to the embodiment work by these researchers, because the current study involved children who directly experienced illness and surgery.

According to Williams and Bendelow (2000), the ‘absence’ of children’s bodies in this area of discourse may reflect the general tendency that exists for children’s concerns to remain silent or under-researched (p53). The absence of children’s voices in research and health is acknowledged in this current work, and children’s silence means that knowledge of children’s understandings and experiences is lacking. The finding that their admission to hospital and surgery was an embodied experience of contrasts is an aspect of the research that helps to fill the gap that exists in understandings around embodiment and children. This work therefore contributes to knowledge and understandings in this area.

The embodied experience of anxiety and fear

The physical and emotional threats hospitalisation and surgery posed for children gave rise to anxiety and fear. Emotions are central to embodiment, and according to Williams and Bendelow (1998), the more the body is threatened or endangered the more uncertain it becomes and the more anxious and insecure (p119). Fear and anxiety was found to be a significant feature of the children's experience of hospitalisation. The children's fears were manifest through their behaviours and the things they spoke about. Early and contemporary literature have consistently identified that children experience fear and anxiety about their admission to hospital and surgery. Indeed, since the early work of researchers such as Edelston (1943) and Bowlby and Robertson (1952), children have been identified as experiencing a variety of negative behavioural and emotional responses to illness and hospitalisation.

The child and their family bring with them their expectations as well as their fears and concerns about the procedures they will have; undergoing anaesthetic; pain; outcomes and possible complications; as well as concerns around the competence of the people caring for the child. Children's surgery has been identified as being a difficult, uncertain and traumatic time for parents (Darbyshire 2003, p308), and as the current study has shown, this is the case for the children themselves. Even surgery that health care staff may consider minor and routine, and the circumstances that surrounds that surgery, including hospitalisation, anaesthesia and analgesia, are recognised as important life events for children and their families (Caldas et al. 2004, p911).

Children's emotional situation is integral to their overall well-being and acknowledging their anxieties and responding appropriately is an important part of the holistic care they are provided. There is a clear need for nursing care to respond to children's emotional as well as physical situation when they experience health care and a richer understanding of children's experiences can help to achieve this (Forsner et al. 2005). Indeed, as this study has shown, the emotional factors children experience can present even more of a concern for them than their physical condition. Attending to children's physical needs and practical tasks can take priority for nurses and other healthcareers because of competing demands, increasing patient

throughput and limited time 'to care'. Unfortunately, in such instances, the psychological needs of children can be lost sight of.

Anxiety caused by feelings of being alone: The children felt lonely and experienced being alone during their hospitalisation and a child could feel 'alone' even when surrounded by other people within the setting. The children participating in this study demonstrated an understanding of the meaning of loneliness and were able to report their own loneliness related to their hospitalisation and were thus competent reporters of this aspect of their experience.

A significant cause of anxiety for the children was the idea that their relationships with those close to them, particularly their parents, might be disrupted by their hospitalisation. According to Bowlby's (1969) theory of attachment, separation from children's attachment figures can lead to them experiencing separation anxiety. The processes of hospitalisation, anaesthetic and surgery present important life events for children and as such, separation from parents around these times impacts on children's fears and anxieties.

The finding that separation from parents continues to be a significant fear for children who are to be hospitalised indicates that parental presence is something taken-for-granted in contemporary paediatric care, but this is clearly not 'a given' for children themselves. Children's own perspectives on this aspect of their care therefore inform paediatric practices as they relate to children's separation anxieties for this age group.

The role of the family in the care of children in hospital is acknowledged as being essential to quality paediatric care. Even though current practices support parent's residing with their hospitalised child, there still exists the potential for all hospitalised children to experience periods when they are unaccompanied. The role of the nurse in supporting children in this situation is an important one. Attempts to make the environment less frightening and more child-friendly have been suggested to be some of the ways of easing the children's feelings of loneliness and of being alone. For example, a nurse's friendly presence when the parent is not in attendance, or facilitating games and activities can serve to relieve their boredom and feeling alone.

Parental presence and children's anxiety: In this study, parents were with their child at the time of induction of anaesthetic and parental presence during induction of anaesthesia is a relatively common practice in Australia. However, this is not always the case in all settings, and whether parents are present or not is often at the discretion of the treating anaesthetist (Smith and Dearmun 2006, p32). There are conflicting reports in the literature as to whether children experience reduced anxiety and demonstrate increased cooperation when their parents are present at induction (Kain and Caldwell-Andrews 2005, p603). Many of those reports are based on observational studies, and do not include self-reporting by children. Other studies have shown that parental presence in the anaesthetic room minimises the distress children experience, as well as reducing anxiety (Smith and Dearmun 2006, p32). This current research demonstrates the positive effect their parent's presence had for the children in this study at all points of their hospitalisation, especially at the time of their induction and recovery from anaesthetic. This view is from the perspective of children themselves. These findings, therefore, add to understandings around the benefits of parental presence for children, from their perspective. Parental presence would seem to be in the child's best interest, however, when the decision whether a parent is present at induction of anaesthetic is with the anaesthetist, it may be that the child's interests are given secondary consideration to those of the healthcare professional.

Being cared for alongside adult patients causes children increased anxiety and fear: Children found the sights and sounds of adult patients who were themselves in distress a cause of anxiety for them. These findings are reflected in the literature and recommended standards. For example, *The (Australian) Standards for the Care of Children and Adolescents in Health Care* (RACP 2008) recommend that there should be a physical barrier for both sights and sounds between children and adult patients so that children are not exposed to potentially frightening behaviours. The children's perspective presented in the current study supports findings that seeing sick adults affects children's anxiety and so furthers understandings of this aspect of children's experience.

Competing resources and constraints such as staffing and rationalisations mean that children are increasingly being cared for in adult units or alongside adults in areas

like recovery or emergency departments. This is evidenced by the decrease in the number of dedicated children's units in Australia (AWCH 2008, Bennnett 2009, p3). This situation was also a finding contained within the *Garling Report* that investigated acute care services in NSW public hospitals. Garling (2008) expressed concern about the increasing trend and for the welfare and recovery of children when they are cared for alongside adult patients:

There is a need to provide dedicated beds for child patients, given the takeover of beds by adults in NSW hospitals, particularly chronic and complex patients. The increasing demand for beds has adults in paediatric wards and children in adult wards... Such a practice which is to my observation quite widespread throughout public hospitals in NSW not only fails to meet the standards dictated by best practice but is risky to the welfare of the child and potentially harmful to their recovery from illness. Most right thinking people would be surprised, perhaps horrified, that this practice is not uncommon (p114).

The role of paediatric nurses as strong advocates for paediatric services that are consistent with recommended standards for care of children in healthcare is a vital one, for children themselves do not have this kind of political voice and influence.

Anxiety caused by not knowing: Children, particularly those with no previous experience of hospitalisation, came to the situation with limited knowledge, expressed in this study as 'not knowing'. Experiencing the unknown and not understanding increases the anxiety of people of all ages who are to undergo surgery, children included. The literature recognises that it is normal for children to be afraid of new and potentially threatening situations especially when the child is not able to fully understand the threatened dangers, or exercise control over them. Whilst childhood fears are recognised as normal, the fears children hold can be the cause of significant distress and impairment (Muris et al. 1996, p265).

Developmentally, the children participating in the study were largely in the concrete operational period described by Piaget and in this stage children develop operational thinking processes that allow them to increasingly use logic in their problem solving. The imaginary threats that are dominant for younger children are less apparent and children of primary school age tend to think about existential questions, for example, in relation to disease when faced with hospitalisation (Hagglof 1999, p73). Children of this age are more able to deal with the stressful components of admission to

hospital in a more realistic way than children of a younger age. As has been previously noted in this work, however, health research with children has demonstrated that their understanding of illness does not only relate to developmental age, but also includes previous experience and severity of illness (Crisp et al. 1996) and coping styles of the individual child. The ways children use to cope with the experiences of hospitalisation and surgery presents an important part of the meaning-making processes they are engaged in.

The unknowing that the children experienced is a concept that is close to the concept of uncertainty. Uncertainty is described as a dynamic state, where there is an inability to assign probabilities for outcomes. Uncertainty arises out of doubt or not knowing, and gives rise to discomfort or unease (Penrod 2007). The discomfort or unease experienced by children participating in this research can be compared to findings by Darbyshire (2003) around uncertainty experienced by mothers caring for their child's recovery from surgery. For the uncertainty experienced by mothers to be alleviated, Darbyshire contends that there needs to be a 'fundamental culture of respect for parents' and children's perceptions, understandings and experiences' (p304). Darbyshire calls for nurses to notice that parents feel anxious or confused or uncertain, and for nurses to understand what parents are going through. The current research indicates that the needs of parents can also be applied to the nurses' understandings of children's experiences of unknowing and uncertainty.

Uncertainty can be mediated by feelings of confidence and control (Penrod 2007). It was through their developing understanding, and the process of coming to know, that the participant children increased their feelings of confidence and control, and decreased their sense of not knowing or uncertainty.

In the current study, parents of the children worked to address their child's need for information whenever they were able, but when parents themselves do not have the required knowledge, or were perhaps even misinformed, there is a further problem. Parents may try to tailor the information their children are provided about their hospitalisation according to both their own level of understanding, as well as that of their child. This means that parents can make judgements about the level and content of information they provide so as not to overload their child with information or cause them additional anxiety (Darbyshire 2003, p296).

The embodied experience of pain

Pain remains a significant feature of children's illness and treatments and all of the children in this study experienced some degree of pain. Pain was an embodied experience for the children that had physical, emotional and psychosocial features. For children, as well as adults, pain is a complex and variable phenomenon and many internal as well as external factors affect the experience of pain (Kortesluoma and Nikkonen 2004, p226). Pain experiences are an unpleasant mix of sensations and emotions (Kortesluoma and Nikkonen 2004, p227) and the psychosocial context can influence the way the child experiences pain. This reflects the integration that exists in mind-body-world relationships described by Benner (2000, p5). The dominant medical model of pain has focused on the physiological aspects, to the exclusion of the mind and culture (Benner 2000, p8).

The situation-specific child factors and the context of pain influence the child's response to pain. The context of experience includes the child's emotional state and the child's expectations. The interactive nature of the pain experience for children and the social context within which children experience pain are also important aspects of that experience (Woodgate and Kristjanson 1995, p244). The social and environment includes parents and nurses' interactions with the child. Children talked about their emotions, including their fears, about anticipated pain from procedures – particularly needles - and surgery. One child talked about how she lay on her mother and rubbed her tummy when she experienced pain. Here it is evident that the embodied nature of her pain experience had both physical, emotional and psychosocial aspects. The physical touch and lying with her mother provided both reassuring physical contact as well as emotional comfort.

For many of the children, the pain associated with their condition and surgery represented the most pain they had experienced to that time. Some paediatric surgical procedures that may be considered 'minor', such as tonsillectomy, circumcision and strabismus repair, can result in considerable pain for children (Finley et al. 1996).

Children who had previous experience of surgery (or other painful procedures) described similar pain to the children who had no previous experiences and this is consistent with findings by Kortesluoma and Nikkonen (2004). One difference

between these groups is that children confronted with new situations feel unsure about what will happen and how they should behave (p226). Whilst the amount of pain does not decrease with repeated procedures, the amount of fear the child experiences may decrease, especially if they receive appropriate support and management at these times. Decreased fear means that the child is better able to cope with the situation. However, the reverse is also true and children who have bad pain experiences may feel helpless, anxious and depressed and their coping skills undermined. Children also become sensitised to pain and when pain is undertreated their pain becomes harder to treat (RACP 2005, p9).

The children spoke of their pain and the methods they used to deal with it. Parents have reported feeling helpless when their child is experiencing pain, unable to do more than provide comfort to their child ‘cuddling and holding them, trying to get them to sleep or distracting and amusing them’ (Darbyshire 2003, p299). The children’s perspective, revealed in the findings of this study, is that when they were experiencing pain, being with their parents, and the comforting strategies parents utilised to support them, were helpful and important to the children. Being with parents is an important social support coping strategy children utilise to help them deal with this experience. Their families are a rich resource who help children be less stressed, and who help children deal with their experience of pain (Carter 2002, p29).

The children thought treating their pain was an important aspect of the nurse’s role, and the children relied upon their nurse to do so. A trusting relationship between children and nurses provides children with some sense of control over what happens to them in hospital. The trust that children have in nurses needs to be reconciled with the finding that children’s pain, in this study as well as more generally, remains undertreated.

Effective communication with the child is necessary in the nurses’ assessment of the child’s pain. Research has shown that parent’s and nurses’ assessment of pain does not necessarily correlate with the child’s own assessment. Nurses assess pain from an adult’s point of view, and do not understand the child’s viewpoint (Kortesluoma and Nikkonen 2004, p211). By researching children’s experience of pain we may be better able to understand their experience of pain from the child’s perspective.

There is a significant body of evidence, standards and protocols and advances in effective treatments for children's pain. Despite evidence based guidelines for practice in the important area of pain management, children's pain is not recognised or managed effectively and continues to be undertreated (Kost-Byerly 2002, p126, Kortessluoma and Nikkonen 2004) and the findings of this study support this notion.

Pain that continues following discharge is another area of concern for the care of children who undergo surgery and knowledge about this aspect of children's pain management is limited (Sutters et al. 2007, p141). Children's experience of pain following discharge was identified in this research, as well as in other studies (Darbyshire 2003, Sutters et al. 2007). With increasing rates of day surgery admissions and shorter periods of hospitalisation, increasingly children's recovery takes place beyond their hospitalisation. More detailed study of this aspect of children's experience of surgery presents an area for further investigation.

Prevention and treatment of children's pain can reduce morbidity and mortality rates in the postoperative period (Kost-Byerly 2002, p115). Other very important reasons for the prevention and treatment of children's pain have to do with humanitarian concerns and children's rights (as acknowledged in the UNCRC) because pain, fear and distress adversely affect the child's quality of life and impinge on their rights.

The children participating in this study were competent reporters who had direct experience of pain and so were a trusted source. This research supports the view that children are capable of reporting on their own experiences of pain, its effects and interventions that can assist in reducing their pain. Although there is an increasing amount of literature on children's pain, when compared to that relating to adult's pain, the number remains few. Research on the pain experience of children, from the child's perspective is even more difficult to locate, as research in this area tends to focus on parental reports and observations of healthcare professionals (Kortessluoma and Nikkonen 2004, p210).

In summary, effective pain management is an essential part of paediatric practice. Understanding the meaning and experience from the child's perspective facilitates care, and understanding the child's experience of pain will improve practices in this

area of paediatric nursing (Twycross 2008, p3212) and further enable care for children in holistic and child-centred ways.

Fun as part of the embodied experience

The things that the children found positive about being in hospital were an important part of their experiences. 'Having fun' emphasises the socio-cultural aspect of their experience. The embodied nature of 'having fun' included the children's physical participation in play; their emotional engagement with humour and laughter and their psychosocial interactions with others. Children enjoyed engaging in physical activities, like playing games and watching television as well as their social interactions with other people, including parents and extended family, and hospital staff. Previous studies have tended to focus on the fears and concerns of children (Coyne 2003) and there is little focus within the literature on those things that children find enjoyable. Studies that have included positive aspects of hospitalisation from children's perspectives are those by Carney et al (2003) and by Curtis et al (2004)⁶. Exploring with children their perspectives of the things they enjoy about hospital as well as those they find difficult results in a broader understanding of the entire experience from their perspective (Curtis et al. 2004). Such understandings of children's perspectives inform paediatric care practices.

The importance of play in the child's hospitalisation: Play was a key element in relieving the fear and anxiety of the children as they were exposed to new and strange experiences. Normal play enables children to relax as they find comfort in familiar activities. This form of play for hospitalised children also enables the continuation of their physical, emotional, social and intellectual development. It provides a safe outlet for children to express their fears and an opportunity for them to assimilate the new experiences they are faced with. Play can increase the child's ability to cope with their hospitalisation and therefore achieve a sense of control; facilitate communication between the child, parents and nurses; decrease stress and

⁶ The research by Carney et al explored a broader range of children's experiences of hospitalisation, and found that the identified themes were generally positive, and that more positive (or neutral views) often outweighed the negative views of hospital. In the research by Curtis et al, children and young people aged between 4 – 19 years discussed both the good and bad things about hospital and community settings.

anxiety; and lessen developmental regression that children can experience during hospitalisation (AWCH 2002).

The children were found to enjoy humour with staff and the times that nurses told funny stories or pulled funny faces to make them laugh. Humour was a successful strategy nurses utilised in establishing therapeutic relationships with the children. Humour is described as a nursing intervention that nurses utilise through tone of voice, facial expressions and laughter (Sheldon 1996, p1181) and provides an avenue for communication between the nurse and the child. Humour was used by nurses to build rapport and a relationship with children. Communication by the nurses using humour indicates their caring and humanness and of being in-tune with the child. Appropriate use of humour helps to break down barriers and establish the nurse-child relationship. It is also a way of reframing a situation (for example the child's transfer to theatre was made less stressful through the use of humour). Studies have shown the benefits of humour on physical and psychological wellbeing (Vagnoli et al. 2005, p563), and the role of humour in providing quality paediatric nursing is an important area of nursing that can be further explored (Pelander and Leino-Kilpi 2004, p148).

The importance of this aspect of children's hospitalisation has implications for care practices in an environment where rationalisation and funding constraints are a part of the healthcare scene. The value of 'play' may be seen to be an unnecessary extravagance and a 'nice to have' in such a climate, but as demonstrated in this study, opportunities for play and fun remain essential components of the care for children in hospital.

In summary, the phenomenon of the children's admission to hospital presented an adversity for them and was an embodied experience of contrasts that included the children's fears and anxieties, their experience of pain and of having fun. These aspects of children's hospitalisation and surgery, from the perspectives of children themselves have been revealed in this study.

The processes

Grounded theory emphasises analysis of action and process and considers what is happening within the studied situation. The identified processes the children were engaged in provided an understanding of how the children moved through the

experience of admission to hospital for surgery. The children were engaged in the processes of ‘coming to know’ and of ‘bouncing back’ and both of these processes were important to their coping and resilience and ability to reintegrate and so move on.

Coming to know

‘Coming to know’ was the basic social process that described the actions and interactions the children engaged in as they made meanings of their admission to hospital and surgery. The major category ‘coming to know’ was raised to a concept, because of its power and reach and its relation to other categories of developing understandings, participating in care and locating their selves (Charmaz 2006, p139).

Children’s coming to know about hospital and surgery was found to be multifaceted; contextual and dynamic. Children’s developing understandings were gained through their own interactions with the environment, as active meaning makers, as well as through their interactions with others who provided social support networks to the children. The children’s own constructions and knowledge of their experience was constructed on the understandings the children gained through these processes and their unique personal and practical experiences (Carter 2002, p37).

The process of coming to know was initially conceptualised as a continuum ranging from a position of ‘not knowing’ and moving toward a position of ‘knowing’. This conceptualisation allowed for the different entry points individual children had in the process of coming to know. However, representation as a continuum did not fully explain the process the children were engaged in. It did not indicate that throughout the experience of admission for surgery there were periods of less certainty as the children encountered new experiences within the broader experience. These new experiences caused them to feel renewed anxiety and uncertainty. That is, children did not move through the experience in a linear direction, but rather experienced times of less knowing even as they were ‘coming to know.’ This dynamic process is represented diagrammatically in Figure 14.

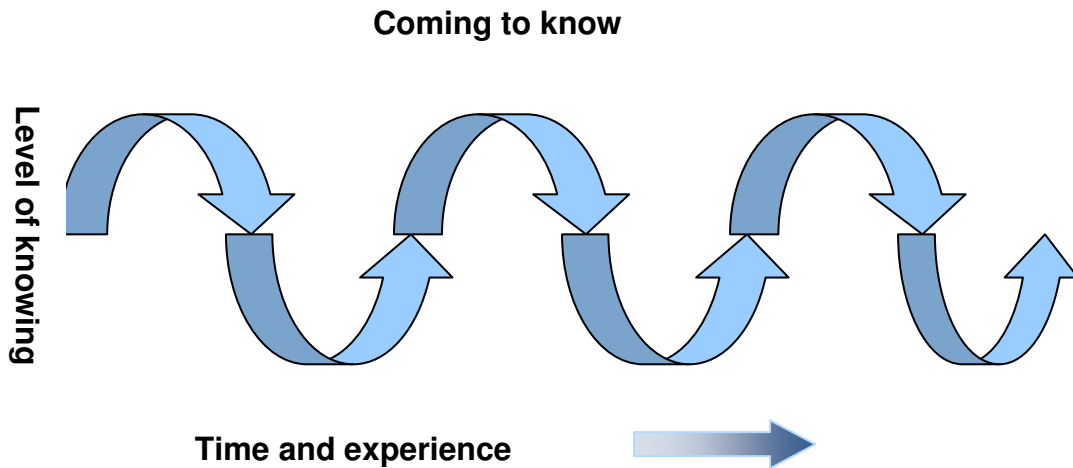


Figure 14: The 'coming to know' model

The '*coming to know*' model captures the dynamic process the children were engaged in, and takes into consideration changes in levels of knowing, that occurred with time and experience.

Children's developing understandings: Understandings were seen to be different among the different children, and individual children demonstrated different understandings over time. These differences might be due to a number of factors, including the child's stage of cognitive development; whether they had previous experience of hospitalisation and surgery; the amount of information that had been provided to the child; whether that information was provided to them in a developmentally appropriate form; or whether factors like stress prevented them from taking in the information they had been given.

Preparation of children for their admission to hospital includes provision of age appropriate information that can help them to anticipate what will happen to them. When children receive appropriate information about their surgery, their coping ability increases and their levels of anxiety are relieved (Dregar and Tremback 2006, p779).

According to the literature, children have different experiences of their level of involvement in their care, and they also experience less than optimal communication with health care providers (Coyne 2006b, Smith and Callery 2005). Even though the

importance of addressing children's information needs is well established, operationalising and implementing this remains problematic (Carter 2002, p37). This presents a further instance where the realities of practice need to be reconciled with findings that children want to be involved through being provided information, and that this involvement increases their sense of control (Coyne 2006b, p68, Alderson 1993). The following quote from Davie (1996) refers to the important contribution that children can make:

The child after all can provide – given the chance – unique often vital, information about the matters under consideration. Sometimes, this may be of an objective nature, where the child as informant can provide data which no-one else is in a position to do (cited in Carter 2002, p37).

In addition to the benefits of including children in information sharing for the reasons provided by Davie above, including children in their care is a recommendation for the care of children in healthcare as well as a child's right. The provision of suitable information to children and their parents presents an important source of empowerment for children.

However, there has been a concerning trend towards *reducing* preparatory interventions for children who are undergoing surgery, even as children's rights to participation and information are acknowledged. The trends in healthcare management toward reducing costs and waiting lists, as well as the time children will spend in hospital may have also led to a decrease in preventative actions that help to alleviate the negative impacts of anaesthetic, surgery and hospitalisation on children (Caldas et al. 2004). None of the children participating in this study for example, had access to a pre-hospital familiarisation program. The most appropriate ways for this kind of information to be provided to children who are to be admitted to hospital, within the current contexts of care, raises further questions and a place for further research.

The children's need to understand their experience was an important aspect of their making sense of the experience. The study confirms the importance of developmentally appropriate information, explanation, and knowledge for children who are hospitalised and provision of these were identified by children as essential to their understanding, coping and sense of control. The provision of such information

therefore assists children in making sense of their experience. Children also require ongoing information throughout their hospitalisation, and for discharge. The study found that information and explanation were not always provided to children and that children themselves find this troubling.

These findings add to the literature around children's need for information that is individualised for their situation (Gordon et al. 2002, Smith and Callery 2005). It also reflects the importance of children's participation in their healthcare that affords them recognition and respect and that reflects a broader concern for children's rights (UN 1989).

Achieving a sense of self and a sense of place: The process of 'coming to know' required the incorporation of their experiences of hospitalisation and surgery into the children's sense of self. The significant event of surgery influences children's feelings about their hospitalisation, their illness or condition and the meanings these hold for them, and how these are incorporated into their sense of self.

A fundamental task of childhood is to achieve a sense of identity and a secure sense of self. Self concept is the accumulation of knowledge about the self, such as the attributes, physical characteristics, abilities, attitudes, values, and roles (Berk 2006). The self is a complex process of gaining self awareness. Self-concept is developed or constructed by the individual through interaction with the environment and reflecting on that interaction. This dynamic aspect of self-concept indicates that it can be modified or changed. Social and environmental contexts shape reasoning and meaning making and how children ascribe meaning to words and experience (Bempechat and Drago-Severson 1999). This view of meaning making is expressed in pragmatic philosophy in the works of Mead (1934), among others.

Place is not just an issue of location (James et al. 1998, p39), nor is it a 'neutral physical surface upon which social action occurs' (Barker and Weller 2003, p209). Place is therefore both a social position and a physical location and these two meanings overlap considerably. 'Places do not exist in and of themselves' and conceptions of place are continuously negotiated and reformulated in the light of exposure and experience (Fog Olwig and Gullov 2003, p7). The hospital environment, like any other environment, consists not only of spatial and physical

attributes (for example objects, length, size), but also of meanings derived from social, cultural and organisational systems (Matthew 1992, p5).

Hospital represents an institutionalised space, designed and controlled by adults, where children have little or no control over what happens to them. Hospital is not a part of the child's everyday world but rather presents both a foreign space and experience for them.

Children's hospitals and children's units are more 'family friendly' and are more welcoming in their appearance than was the case in the past. However, they are still unfamiliar, for both children and their families. Darbyshire (2003) stated hospitals are 'difficult places for parents to be in, both physically and existentially, as they do not speak the language, know the codes or understand the customs and geography' (p292). If this is the situation for their adult parents, then for children, these difficulties must be accentuated. Admission to hospital has its own set of rules and behaviours that are quite different to anything the children will have experienced in their every-day lives. Coyne (2006b) refers to the social order of the ward that is different to the child's known social world (p65).

Finding their 'place' within the hospital setting was important for the children in order for them to incorporate the experience into their sense of self. Links between the familiar and the unfamiliar facilitated the children's development of a sense of place and 'locating their selves'. Making a sense of place is a multifaceted process (Matthew 1992, p2), involving transactional behaviour. Children were both influenced by and also influenced the environment through a reciprocal and adaptive process. It was through experiences like play that the children gained an understanding of place. In addition, each child processed the environmental information, and each child processed this information differently, so they therefore experienced the environment differently. These notions of meaning making are reflective of symbolic interactionism.

Schemes, adaptation, organisation, assimilation and accommodation: The children's previous experience (or lack of experience) of illness, admission and surgery significantly influenced the understandings of their (current) experience; influenced what they knew and the depth and range of that knowledge. The children

were active learners who actively constructed knowledge as they were engaged in the phenomenon and this position is consistent with Piaget's (1950) theories around the development of schemas and the processes of adaptation; organisation; assimilation and accommodation. The concepts of schema, adaptation, assimilation and accommodation informed the conceptualisation of the children's 'coming to know'⁷.

Event schemas or scripts are defined as organised sequences that outline the actions, actors and props most likely and least likely to occur during an event (Hudson et al. 1992, p483). The organising of events that synthesizes experiences in a narrative is called emplotment (Ezzy 1998, p245). The integration of events into a story, in ways such as those illustrated in the findings chapter, helped the children to make sense of their experiences. Children were able to build scripts from events they experienced, or from the way they imagined an event would play out (Smith and Callery 2005, p233, Eiser et al. 1990). Being given appropriate information also assisted children in this.

Scripts also help in the recall of past events and children are able to draw on this information to predict future events. Participant children who had no previous experience of hospitalisation or surgery had very few, or non-existent schemes of these things to draw upon. These children had to accommodate or form new schema that became a representation of the experience in order for them to make meanings of their experience. On the other hand, children who had experienced a previous admission and surgery were able to draw on their pre-existing schemas of hospital and surgery and so assimilated their current experience with their previously existing structures or schema of hospital and surgery.

Children's scripts become more elaborate and complex with increasing age and with increasing experience of an event. By using the impersonal pronoun (you) and the timeless present tense, the child organises the event as a set of expectations that the event will be structured in a similar way (Hudson et al. 1992). A number of children

⁷ Recall that schemes are used to make sense of the world; that assimilation uses current schemes to interpret the external world and accommodation requires the formation of new schemes, or the modification of existing schemes, according to the external world. Organisation of schemes involves a process where children rearrange and link schemes; including the new ones they have formed Berk, L. (2006) *Child Development*, Pearson, Boston..

gave organised accounts of events, using 'you' and the present tense. Some examples of these were presented in the previous chapter (for example, page 195). The children described moving through different spaces - of going from this place to that; the different spaces they occupied, including the ward, the emergency department and the operating suite; as well as the people in those areas. Children tracked or mapped their experience through the admission and by describing the journey 'from here to there' children were able to organise events, and make sense of where they were.

The findings indicated that all children experienced anxiety about interventions or procedures such as injections and insertion of cannulas. It was evident, however, that children who had a more secure sense-of-self within this environment, or who had some level of control over such events, were able to draw on positive coping strategies to help them deal with these procedures. This was a significant finding of the research that supports the important positive effects of resilience and protective factors on children's abilities to bounce back from the adversities they face when hospitalised.

The way that children remember a procedure has a significant impact on the way they come to subsequent medical experiences. For example, children's responses to previous pain experiences, and the recall of medical procedures has been associated with children's anticipatory anxiety for future procedures (Chen et al. 1999). The child's description of how a cannula is inserted (p185 of this work) is an example of how a prior experience positively impacts on the child's attitude to future procedures. It has also been recognised that the provision of appropriate information about their care and procedures allows children to better understand events and to experience them as more predictable and less stressful.

As previously identified, there are three basic assumptions of symbolic interactionism. Firstly, people, as individuals and collectively act on things on the basis of the meaning they have for them. Secondly, meaning arises on the basis of the process of interaction, and thirdly, meanings are modified in an interpretive process that is ever changing and subject to redefinition, relocation and realignment. By selection and interpretation, the children formed new meanings and new ways to respond and were therefore active in shaping their own self through the process of interpretive meaning.

The process of ‘coming to know’ led to the children having a sense of increased control and reduced anxiety. Their coming to know was through their own agency as well as through their interactions with their environment and with others.

Bouncing back

The second basic social process identified was ‘bouncing back’. Although they expressed anxiety about their hospitalisation and having surgery and generally did not like the idea, they were able to accept the need for their operation and they demonstrated an acceptance of these realities. Children also demonstrated that they were able to move on and ‘bounce back’ from this experience that was a form of adversity for them.

The constructs of resilience and coping

The children’s resilience and coping were seen to be key to their ‘bouncing back’ and the theoretical constructs of resilience and coping were drawn upon in the conceptualisation of ‘bouncing back’. The constructs are both complex and closely linked. The term ‘resilience’ is derived from Latin roots meaning ‘to jump or bounce back’ (McElwee 2007, p58) and coping has been identified as a defining attribute of resilience.

Resilience: Resilience in children has been defined as ‘children’s developing capacities to use coping strategies (for example, distraction, changing thinking, exercise, seeking support etc) that help them regulate the intensity of negative emotions they experience in the presence of adverse events’ (Bernard and Pires 2006, p158). The qualities of resilience include bouncing back and moving on with life after experiencing an adversity as the individual wants to get back to normal, to reintegrate or assimilate with their familiar way of life. Other qualities include: self-determination and self-worth; at least one healthy attachment to a significant adult; flexibility; a sense of humour and the ability to make light of adversity; self-esteem and self efficacy (Earvolino-Ramirez 2007).

A number of these qualities were demonstrated by children in this study. Children were seen to want to get back to normal, to reintegrate or assimilate with their familiar way of life. Following their recovery from their surgery, the children demonstrated a desire to move on from their experience. ‘Reintegration’ describes

the process after disruption or adversity (as was their experience of admission to hospital and surgery) where an individual wants to return to a regular routine or ‘get back to normal’ (Earvolino-Ramirez 2007, p76). The process of reintegration was presented in different ways by a number of the children in interviews held following their discharge from hospital. For example, recall the child who said he no longer thought about his experience of surgery and the girl who proudly showed me the scars she bore.

The children participating were active agents in their experiences and the very important role their parents and other family members had for the children was evident – the children in this study had healthy attachments to a number of significant adults (including parents and for a number of children, grandparents).

Optimism, or looking on the bright side, is an important construct of resilience (McGrath and Noble 2003, p5) and being optimistic is a belief that setbacks are normal and can be moderated by our own actions. An overall sense of optimism was displayed by children. Humour is a feature of optimism and the children’s use of humour was seen to be one of the things they enjoyed about their hospitalisation and their interactions with others. Humour also promotes hopefulness and presents a strategy to diminish anxiety and increase children’s confidence and control (Sheldon 1996). Humour in this instance presents a positive coping strategy.

An optimistic outlook empowers children and helps them overcome the challenge hospitalisation and surgery presents and is an example of positive reappraisal and positive refocusing. Strategies such as these are ways children are able to tolerate or master the negative life experiences, in this instance, hospitalisation and surgery (Garnefski et al. 2006, p2).

Coping: Coping is defined as ‘constantly changing cognitive and behavioural efforts to manage specific external and /or internal demands that are appraised as taxing or exceeding the resources of the person’ (Lazarus and Folkman 1984, p141).

According to Lazarus and Folkman’s (1984) model, coping is a multidimensional process that is affected by personal, temporal and situation-specific variables.

The children demonstrated active coping strategies that included direct problem solving, seeking understanding, cognitive decision making and cognitive

restructuring. These strategies represent purposeful and constructive attempts to actively manage the stressor that hospitalisation and surgery presents. These ways of managing situations are associated with healthy responses. But illness and hospitalisation and surgery are stressors that are largely out of children's control, where they are not in a position to eliminate or prevent the situation.

Social support systems have been identified as crucial factors in successful coping and parents and family are predominant sources of social support for children. The active coping strategy of social support presents an important strategy in situations that are not in children's control and children increasingly rely on support from adults when they are in a situations that are uncontrollable or where adults have authority (Skinner and Zimmer-Gembeckz 2007, p129). Well established social supports assist resiliency and act as a buffer to stress through their impact on self-esteem, perceptions of control, social integration and coping (Pinkerton and Dolan 2007, p220).

Pain was clearly a major concern for the children associated with both their condition and surgery and was something they were not able to prevent. However, the ways that children respond to pain and are able to deal with the physical and emotional burden it presents them is an important feature of their coping and ability to bounce back.

There are few studies of naturally occurring coping strategies used by ill or injured children (Landolt et al. 2002). Although exploration of natural coping strategies was not a part of the initial research question, this research has provided an understanding of children's use of such strategies when experiencing the phenomenon of admission for surgery.

The process of 'bouncing back' described how children were able to reintegrate and move on from the adversity of their hospitalisation and surgery. 'Bouncing back' incorporated the children's resilience and coping strategies as they dealt with their hospitalisation and surgery - situations that were largely out of their control. The process of 'bouncing back' also reflects the children as active agents embedded within the phenomenon.

The context – a facilitating environment

A facilitating, holding environment such as described by Winnicott (1965) was essential for the children to build understandings of their experience and for them to successfully incorporate their hospitalisation and surgery into their sense of self. The enabling environment includes both social and physical aspects. Naming the concept of the holding environment as a gerund ‘being held’ reflects the active nature of the notion of holding, and also represents the concept from the perspective of those being held – that is the children themselves.

Being held

‘Being held’ represents the facilitating and supportive environment necessary for the children during their experience of illness and surgery – times that Winnicott (1965) described as a period of crisis for the child (p149). The literal and metaphoric notion of holding was used by Winnicott (1965) to describe how the infant only knows an all-encompassing domain which includes physical and psychological care, and the anticipation and provision of needs (p149). Holding environments, as discussed previously (p35), describe the nature of effective caregiving relationships, considered to be intrinsic to human development for it is ‘within holding environments, [that] people demonstrate their care and concern for others in particularly skilful ways’ (Van Buskirk and McGrath 1999, p808).

Context and situatedness were not emphasised in the original grounded theory work of Glaser and Strauss. However, Strauss and Corbin (1998) engaged situatedness, and the work of Clarke (2005) also emphasises this aspect in grounded theory (pxxxv). Charmaz (2006) argues that situating grounded theories in their social, historical, local and interactional contexts strengthens them (p180). The context of the studied phenomenon was found to be an integral consideration for this work.

The children’s resilience and ability to ‘bounce back’ was sustained and nurtured by a caring and facilitating environment. Environmental influences that foster and support resilience are called protective factors and in this study, protective factors were the attributes or situations that were necessary for the process of the children’s resilience to occur (Earvolino-Ramirez 2007, p75). These factors enabled them to successfully deal with the difficulties of hospitalisation and surgery. Risk factors

were the environmental factors that tended to inhibit their ability to face and surmount challenges. When present, protective factors could limit or negate the effects of risk factors in the children's environment, allowing their innate resilience to help them succeed. The notion of a facilitating environment and protective factors that support resilience is similar to the holding environment described by Winnicott.

Protective factors help children to negotiate situations that they perceive as a significant risk. Protective factors include biological, psychological and environmental components that contribute to preventing a stressor, lessening its impact, or ameliorating its effects more quickly. For the children admitted to hospital for surgery, a major protective factor are those processes that are supportive of parental presence.

Protective factors are contextual, situational and individual and can be organised into three categories: 1) individual characteristics; 2) family and 3) community. In the context of children's admission to hospital, in order for resilience to flourish protective factors within these different categories include: children's own personal qualities; their family - most particularly their parents, but also siblings and extended family; the hospital setting (for example, staff and other hospitalised children) as well as their more familiar community, such as their school and their friendships. A nested model of supports for children admitted to hospital for surgery is presented in the Figure 15. This model demonstrates how the central focus is with the child and also recognises the primary role of parents and family in supporting the child. In addition, the supports of wider family and other networks are recognised; and healthcare workers work with children and their families to support them through the experience of the child's hospitalisation and surgery. When supports are effectively in place, children (and their families) are better placed to be able to cope and 'bounce back'.

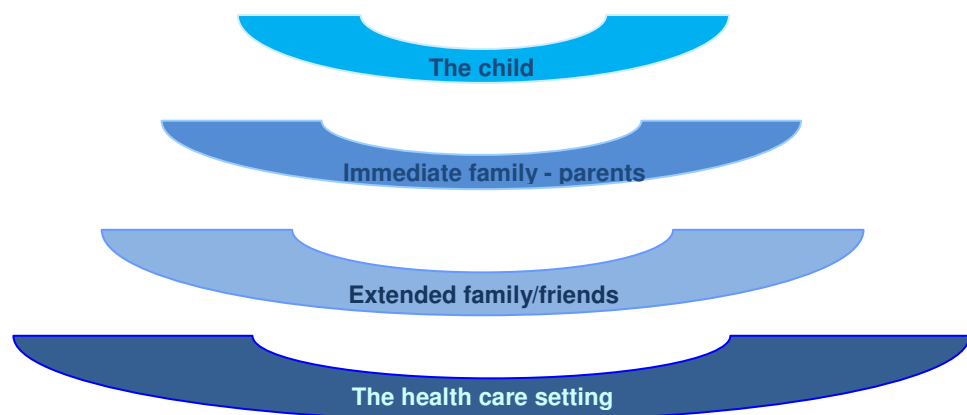


Figure 15: The nested model of *'being held'* (adapted from (Pinkerton and Dolan 2007, p221)

‘Being held’ by parents and family: An important aspect of the children’s hospitalisation is the critical role of parents and other family members, and the children place great reliance on the support of - or ‘being held’ by - their parents. Their parent’s presence limited or contained the negative effects of hospitalisation for the children, that included separation, fear, the unfamiliar environment and the effects of their illness (Coyne and Cowley 2007, p894). Although the experience of parents was not a focus of this study, their experiences have a direct impact on the whole family unit, including the hospitalised child (Hopia et al. 2005, p213).

Children identified that their parents looked after them while in hospital, and that nurses took care of them in the absence of their parents. Yet the level of involvement families themselves are able to undertake, or choose to undertake, cannot be taken for granted by nurses. Research has found that parents can feel burdened by expectations that they have a role to provide both childcare and nursing care, when they see their role as primarily one of being there for and being with their child (Coyne and Cowley 2007).

This research also showed how the children relied upon their parents to provide them with information. In turn, parents’ access to information is important to the ways that they manage their child’s illness. Yet research indicates that parents do not receive

adequate information and support when their child is in hospital (Hopia et al. 2005, Sarajarvi et al. 2006).

The role of nurses in supporting children and families: The children in the study valued personal qualities of the nurses - that the nurses were 'nice' and 'kind' and that they had fun with the children. They also valued being able to trust that nurses would provide them with the care they required to support their recovery, including providing them with information; personal care; medication administration and attending to their needs promptly. When nurses did not do these things, the children's trust in the nurse was reduced and impacted in a negative way on their experience of 'being held'.

Ways that nurses can support children in their experience of admission for surgery and the implications for paediatric nursing care have been identified in discussion points in this chapter. The critical importance of understanding children's experiences from their perspective has been highlighted, for example, in relation to children's own experience of pain. The need to respond to children's emotional as well as physical situation; of providing a supportive and friendly presence; the importance of play and the therapeutic use of humour have also been identified. Other ways for nurses to provide support are by empowering children by including them in care and providing appropriate information; and in supporting children's positive coping strategies. The value children placed on nurses' engagement with humour and fun stresses the importance of play for children who are hospitalised. It also emphasises that as well as demonstrating competence in the technical aspects of nursing, a defining attribute of paediatric nursing is having an understanding of, and providing developmentally appropriate care to children.

As discussed, family centred care is central to the way paediatric nurses work with children and families. The provision of family centred care is complex, relational, dynamic and subject to the influence of internal and external factors (Carter 2008, p2093). In addition, the effectiveness of family centred care for children in hospital is unclear and its implementation problematic (Shields et al. 2006, Corlett and Twycross 2006). An essential task of paediatric nursing is in monitoring and assessing the whole family's situation and in identifying and supporting families own resources (Sarajarvi et al. 2006, p205). A measure of the quality of paediatric nursing

care can be how nurses help parents themselves manage during their child's hospital stay (Hopia et al. 2005).

It is difficult to perceive the creation of a holding environment for children admitted for surgery without those providing care to the child and family actively seeking empathetic understanding of the child's perspective of issues, ideas and concerns (Babits 2001, p27). Interventions to limit the negative effects of hospitalisation have gone some way to improving children's experiences, however, emphasis on nurses providing sensitive support and care for children and their families in the children's hospitalisation and recovery remains an imperative.

There has been little exploration with children as to their perceptions of the role of nurses. Studies that have been conducted include those by Carter (2005); McDonald and Rushforth (2006); and by Brady (2009). Findings from this current study add to the understandings these works provide on the role of nurses who care for children. An understanding of children's perceptions of the qualities they value in nurses informs nurses' practice and in doing so facilitates the care that they provide to children.

A child friendly environment: The children's interactions with the environment were important to their sense of well-being and for their 'being held'. Child-friendly features of the environment that facilitated children's positive experiences identified in the study included positive interactions with nurses and other staff members; links with familiar and special things; access to age appropriate activities like play and school; and aspects like ward furnishings and art works. A major aspect of the physical environment was that it should facilitate the children's connections with their main social support system – their parents and family. All of these features contributed to children's feelings of comfort, welcome and control.

These findings are consistent with theories, standards and research about hospital environments, in general and those relating to children (Ulrich 2000, Curtis 2007, Bishop 2008, RACP 2008, Southall et al. 2000). The specific physical environment is recognised as having a major influence on people who are hospitalised. Environments that have patient-centred, supportive characteristics help patients cope

with the stress that accompanies illness by fostering a sense of control; access to social support and positive distractions in the environment (Ulrich 2000, p160).

Just as in other areas of healthcare, there are a limited number of studies around hospital environments that include children's views. Research by Curtis (2007) found that the physical environment is important to children in a number of ways not generally addressed by adult assumptions (p19). Some of the different recommendations for children's hospitals and units, compared to those for adult settings relate to the need for age appropriate activities and spaces and the need to accommodate families and their needs, so that families can fulfil their role in supporting children.

As has been identified in other areas of this work, there are increasing pressures on resources specific to the provision of child friendly services and facilities for children in hospital. This is supported by findings contained within the *Garling Report*:

....when the inevitable increase in the demand for the provision of health care for people over the age of 65 occurs, investment in child health and the health of adolescents is not overlooked or given any lesser priority. It is clear that the provision of inpatient hospital services to children and young people is, speaking generally, on a per person basis, more expensive than the provision of adult health care. Nursing ratios are different. It takes longer to undertake most interventions with children than it does with adults. Surgery is often more complicated (Garling 2008, p114).

Children have a right to care that is appropriate to their special needs, as expressed in the UNCRC (UN 1989) and in standards for the care of children in hospital (RACP 2008, Southall et al. 2000). Environments that are child friendly and appropriate for the developmental needs of children and that facilitate family presence constitute holding environments for children who are hospitalised.

Before concluding this chapter, it is appropriate to reflect on the implications of socio-cultural influences and child development for this research. These areas of concern have underpinned processes in the work and have informed theoretical conceptualisations.

Socio-cultural implications

The importance of socio-cultural influences on children's status in society and subsequent link to the care of children were highlighted in the opening chapters of this work. Attitudes and practices for children's healthcare and hospitalisation have their origins in the status of children in the wider social world. The findings of this study indicate that the social and cultural influences of children's healthcare directly impacts on children's experiences of healthcare.

For example, the 20th century was referred to as the 'century of the child' and by the end of that century, children had acquired rights not foreseen at the century's beginning. The UNCRC (UN 1989) includes a number of rights that relate directly to the provision of children's healthcare, and have therefore informed policy, standards and practices for the care of children in hospital. These policy directions are a part of a strong socio-cultural focus on children's rights in the Western world. This study has reinforced the importance of the role of the family for children who are hospitalised and that children should be cared for by staff who have an understanding of children's special physical, emotional and developmental needs.

The children's ward described in the opening of the thesis is very different to the colourful children's wards in today's hospitals, where play is seen as an essential part of the context of care. It is not possible to picture hospital clowns, for example, in the earlier children's ward, yet their presence in many contemporary wards is well established. The strict rules and regulations for parental visiting from the Children's Hospital in 1947 are also very different to contemporary policies that support parents residing with their hospitalised child.

However, despite these developments that acknowledge children's rights and needs, in some areas of children's healthcare services, previous gains of the last century are being eroded. This reversal means there is less emphasis placed on children and their special healthcare requirements. The deterioration in children's healthcare services impacts upon the healthcare experiences of children themselves. The driving influences for these changes may be society's strong focus on economics and economic rationalism as well as changing demographics of our society. Intergenerational discourses, for example, focus on our aging population and the

impacts this will have on services including healthcare. These discourses do not refer to children's needs (Commonwealth of Australia 2010). Whatever the causes for the erosion of children's status, the results are problematic for the place children have and pose a threat to the provision of the best possible healthcare for children (Southall et al. 2000). In effect, the 'rights of the child' debate appears to be losing to the stronger 'economic rationalism' and 'aging society' debates. The socio-cultural context, where the major concerns of society and politics do not have a focus on children, may see a continued reversal of specialised healthcare services for children, unless the interests of hospitalised children are vigorously promoted.

Child development theories and their application in the research

Theories of children's development, an understanding of children's language skills and the ways children make meanings have informed the research process and methods for this study. Theories of children's development also influenced the theoretical conceptualisations that resulted from analytical processes.

The development of age appropriate assent documents for the study is one example of how the work was informed by child development theory. This is also an example of how this research contributes to the discourse around developmentally appropriate research methods for research with children.

The approaches used in interviews were influenced by understandings of child development – the use of direct questioning, prompts and scaffolding are examples of ways children's meanings were elicited, through the use of developmentally appropriate methods. The length of interviews were shorter than many qualitative interviews with adult participants, and my own voice within the interviews has a greater presence than would be likely in interviews with adults. These differences are a result of the special developmental requirements of children.

The children participating in this study were not viewed as a heterogeneous group. Children were recognised as having different levels of understandings because of their different ages as well as differences in the range of experiences of children - across children and within the same child. So that a child of 8 years who had

previous experience of intravenous cannulation was seen to have more understanding of this procedure than a child of 11 years who had no previous experience of intravenous cannulation. In addition, individual children developed understandings over the time they were in the experience. These findings support previous research that identifies the importance of children's experiences to children's understandings (Crisp et al. 1996, Alderson 1993).

The ways different theories informed the research include the following. Mead's (1934) theories on the development of a sense of self informed the methodological approach to the work as well as the theorising. The findings demonstrated that children were required to reframe their sense of self to incorporate their illness and surgery. Vygotsky's (1978) theories that recognise social and cultural influences on children's development was congruent with the constructivist and symbolic interactionist positioning of the research. Children's social interactions with others and their environment were found to be important to their meaning making processes. Piaget's (1952) theories around scripts and schemas; adaptation, organisation, accommodation and assimilation were also important to theorising about how the children made sense of their experiences and the meaning making processes they were engaged in. Bowlby's (1959) theories of attachment and Winnicott's (1965) theories of the holding environment informed initial understandings and later conceptualisation and theorising processes. A context that is supportive of the bonds children have with their parents reflects Bowlby's attachment theory. The caring interactions children have with those they come in contact with in hospital and a physical environment that is appropriate for children's needs all reflect Winnicott's theory of a holding environment.

Understandings of children's development influences the care that nurses and others provide hospitalised children; how they communicate with them; and include them in decisions about their care. It also influences the physical environment or context of children's hospital care. This reflects broader policies and standards articulating the need for developmentally appropriate care of children (UN 1989), as well as those that specifically relate to care of children in healthcare (RACP 2008, Southall et al. 2000).

Conclusion

A substantive theory of primary school age children's admission to hospital for surgery, from their perspective has emerged through my own interpretive renderings, theoretical constructions and interactions with study data. The substantive theory presented in this thesis is situated in the historical, local and interactional context of the area of study. According to Charmaz (2006):

The end point of your journey emerges from where you start, where you go, and with whom you interact, what you see and hear, and how you learn and think. In short the finished work is a construction – yours (pxii).

Primary school children's experience of admission to hospital for surgery presented a form of adversity to them and was an embodied experience of contrasts, that included 'being scared'; 'hurting'; and 'having fun'. The processes the children were engaged in for reframing their sense of self were those of 'coming to know' and of 'bouncing back'. In order for the children to successfully incorporate the experience into their sense of self, a supportive context or holding environment was necessary, expressed as 'being held'.

The stressful effects hospitalisation has for children is recognised in paediatric literature. Despite attempts to remove or limit the negative effects of hospitalisation for children, this study confirms that children continue to experience negative impacts of hospitalisation. Children continue to experience anxiety and uncertainty that could be eased through information targeted to children and their parents. Children continue to experience pain. The body of evidence, treatments and practice guidelines for prevention and treatment of children's pain suggests this pain is unnecessary. Children also continue to be treated alongside adults, even though best practice and standards for care of children in hospital indicate that this is not in the child's interests and presents cause for concern for children's wellbeing and recovery.

In this study children identified interventions that served to assist in reducing their anxieties, thus increasing children's sense of control. Therapeutic interventions such as humour, fun and play created a contrast to anxiety and fear. These interventions promote coping and well being; empower children; and address some of the negative effects hospitalisation and illness has for children. The child-friendly aspects of their

experience is something that is specific to children's hospitalisation as compared to adult patient's care.

Children viewed their parents as having a primary role in providing their care. The philosophy of family centred care is central to paediatric nursing. Since the last half of the 20th century, parents have moved from being excluded in their child's care to being tolerated and more recently toward being accepted as central participants in their child's care. These changes have reflected changes in society's perceptions of children and childhood that acknowledge children's rights.

The findings from the research highlight the need to include children's perspectives in their health care and in research. Children's knowledge and interest in participation is not always recognised. However, children's rights to active participation and to have their voices heard is acknowledged in the UNCRC (UN 1989) as well as in policies and standards and key reports relating to children's health care. This study of children's experiences, from their perspective has children as the primary source of knowledge about their views and experiences. Children's own experiences and needs as expressed and defined by them is essential for understanding.

The findings are not dissimilar to other, recent studies with children as direct participants in research about their hospitalisation. Similarities include, for example, children's need for parental presence; their need for age appropriate information and to be included in care decisions. These similarities in findings confirm the ability of children to be active participants and trusted reporters of their experiences.

The findings of the study suggest that ongoing problems with paediatric practices continue to impact on children's experiences of hospitalisation. Within a context of increasing financial and resource pressures on health services there is evidence that child friendly practices are being lost. It is through listening to, and hearing children, that health care can move closer to best practice that meets children's needs.

The final chapter includes the significance of the research findings against the aim of the study; an evaluation of the research; and implications for practice and further research.

Chapter 9: Conclusions and recommendations

The end of a work such as this should signal neither a conclusion nor a final word, but rather a punctuation in time that marks a stop merely to take a breath (Lincoln and Denzin 2005, p1115).

This study presents a substantive grounded theory of primary school age children's admission to hospital for surgery, and in so doing provides insight into the phenomenon of children's admission to hospital for surgery, from their perspective. This final chapter focuses on what has been found as a result of the study and how the findings are relevant to the central research aim. A further focus is how this work contributes to the discipline knowledge and, as the above quote suggests, where further enquiry might take place.

What this research adds

The research aim was *to explore children's admission to hospital for surgery from their perspective in order to develop a substantive theory*, and this aim has been achieved. The theory of children's admission to hospital for surgery provides a conceptual rendering of the data that furthers understanding of the studied experience. Theorising entailed engaging with the children and the studied phenomenon and of constructing abstract understandings about and within it (Charmaz 2006, p130). The resultant theory is a substantive theory that furthers understanding of children's experience of this aspect of their hospitalisation. The theory that has been developed rests upon my own interpretation of the studied phenomenon.

The work also contributes to knowledge around children's participation in nursing research. Primary school aged children are little researched, and this work has shown that research with children of this age group can provide valuable knowledge that can further understandings of their healthcare. Children have been acknowledged as being epistemologically privileged in the research and their voices were presented as they described their experiences. It is through actively listening to children that nursing practices can be developed that recognise and respond to children more effectively and appropriately to meet the child's needs (Kortesluoma and Nikkonen 2004).

A constructivist grounded theory approach has been shown to be a method appropriate for use when children are direct participants. Use of this approach has resulted in a rich picture of children's admission to hospital for surgery. The children's perspectives are presented as the central focus, but the work recognises the co-construction that takes place between the participant and the researcher. As researcher, in remaining close to the studied world of children's admission for surgery I was able to develop an integrated set of theoretical concepts from the data that were synthesised and interpreted and that showed the relationships between them (Charmaz 2005, p508).

In contrast to one narrow method of data collection, there was inherent value in employing different data gathering approaches that incorporated child centred methods. Integrating interviews with children, their drawings and stories and my observations resulted in 'listening to' participants; 'seeing and hearing' what was happening and 'being there' (Lambert et al. 2008, p3100). The use of different methods of data collection contributed to the trustworthiness of the study.

Key findings of the research

The research findings and theorising of this work were presented in the previous 3 chapters and are briefly summarised here:

The primary school age children's admission to hospital for surgery was found to represent a form of adversity for them and the children were active participants embedded within the phenomenon that was an embodied experience of contrasts. Major concepts of the children's embodied experience were fear and anxiety, expressed as 'being scared'; pain, expressed as 'hurting'; and positive aspects of their experience, expressed as 'having fun'. Within the phenomenon were two major processes the children were engaged in, in order to incorporate the experience into their sense of self, and so reframe their sense of self. The first was around their meaning making activities, expressed as 'coming to know' and the second was their ability to move on from the adversity and reintegrate, expressed as 'bouncing back'. For the children to successfully reframe their sense of self and reintegrate their experience required the presence of a facilitating holding environment that was expressed as 'being held' and this environment consisted of both physical and social interactions.

The work reveals aspects of the phenomenon of children's admission to hospital for surgery that have not previously been explored; provides new insights to previous understandings; and generates new knowledge. Findings have the potential to influence the care of children who undergo surgery as well as children who experience hospitalisation for other reasons.

Evaluation of the study

The evaluation of the study includes an appraisal of the study strengths and weaknesses; how the standards and criteria for a grounded study apply to this research; and the methodological contributions that the work offers to research that involves children as participants. This section also includes implications for practice and further research.

Strengths and limitations

All research approaches have their difficulties and limitations and acknowledging the limitations of this research does not decrease the value of the study, but rather enriches it by making the underlying assumptions and premises transparent and open to critique.

The findings from this research were drawn from 10 participant children who experienced admission and surgery and was based in one Paediatric Unit of a general hospital. This study lies firmly within the interpretive tradition as the analysis was contextually situated in time, place, culture, and situation (Charmaz 2006, p130-131). Therefore, the findings cannot be representative of all children admitted for surgery and all hospital settings. However, generalisability is not a concept that is a concern in qualitative research approaches and no single method can grasp all of the subtle variations in people's experiences. Qualitative approaches recognise there is no single interpretive truth (Denzin and Lincoln 2005, p8), and that qualitative research is the world of lived experience and so can provide important insights and knowledge (Denzin and Lincoln 2005, pp7-8). This work provides valuable insights for those who care for children to reflect on, appraise and challenge their experiences and practices.

The small number of participants in the study may be considered a limitation of the work, however, the number of participants in this study is in keeping with other

grounded theory studies with children as participants and allows the researcher to investigate each of the participants in greater detail (Woodgate and Kristjanson 1995, p245). The ultimate quality and credibility of the work lies with the richness, depth, suitability and sufficiency of the data (Charmaz 2006, p18).

The subjectivity of the researcher adds a layer of complexity to the research process as the research has been filtered by own lens and my positioning within the research cannot be wiped away. The notion of researcher bias is acknowledged in this study, not dismissed, and is addressed by making my position transparent and explicit through reflexivity. For constructivist grounded theory researchers ‘stand *within* the research process rather than above, before or outside it’ (Charmaz 2006, p180).

This study did not seek the views of other stakeholders, such as parents and health professionals and this could be seen as a limiting factor to the study. However, the aim was to focus specifically on and explore the experience of one group of children from their perspectives. The value of seeking the perspectives of parents and health carers is acknowledged and would add further dimensions to understanding.

A critique of interpretivist constructivist research such as this is that the work does not go far enough in advocating for an action agenda to help marginalised groups (Creswell 2009, p9). In giving voice to a marginalised group, that is children who experience healthcare, changes in care practices can be informed, and even transformed, as a result of increased understandings.

Meeting the criteria for a grounded theory study

Whilst there are a number of standards and criteria for qualitative research, the criteria outlined by Charmaz (2006) for constructivist grounded theory research guided this research project to ensure the usefulness and quality of the final work. The four criteria used to evaluate this study are credibility, originality, resonance and usefulness (Charmaz 2006, p182). Ultimately however, it is the reader who judges the usefulness of the methods and the quality of the work (Charmaz 2006, p182).

Credibility: The research has explored the admission to hospital for surgery from the perspective of children aged from 6 to 12 years engaged in that experience. Analysis of interviews with children, their stories and drawings and my own observations in the field have allowed me to get as close to the children’s experience and the

processes they were engaged in as possible. As is consistent with a constructivist grounded theory approach, I acknowledge that the result of the research is not ultimate truth per se, but is mediated and qualified by my own interpretations and understandings (Kayrooz and Trevitt 2005). That is, the findings are not ‘facts’, but are instead ‘constructed truths’ and the extent to which the constructions are viable and defensible is dependent on my presentation of them to the audience in a way that is meaningful (Thorne et al. 2004).

Throughout the work, reference has been made to where data have been lifted in order to demonstrate that the work is firmly grounded in the data. The ranges of data have provided a rich source from which to make the claims presented. Interviews with children and their stories and drawings have enabled deeper understandings of their concerns and my own observations of children’s hospitalisation and surgery have provided a further data source for analysis and theorising. Observation allowed me to give children a different kind of voice, not through language, but through describing their action observed (Tudge and Hogan 2005, p116). The careful listening, reading and re-reading of taped and transcribed text was an important process for getting close to the data and for having confidence in its overall credibility. The tape recordings of interviews and the detailed transcripts, the ongoing field notes as well as memos maintained during the course of the study have facilitated dependability and reliability. The intention is that as a result, the reader is able to form an independent assessment of the claims made and agree with these, because there is sufficient evidence provided to allow this (Charmaz 2006, p182).

Originality: The current study adds to the body of work that already exists in paediatric nursing and specifically focuses on the understandings of primary school aged children and their hospitalisation for surgery. Other qualitative works have explored the hospitalisation of children, from the various perspectives of children, parents and health care professionals. By privileging the children’s experiences this work offers a fresh and deeper understanding of the phenomenon from the perspective of children. The concepts developed in the work have elements of originality and offer new insights into the processes children are engaged in when they are admitted to hospital for surgery. The analysis of the data, the interviews, stories and drawings and observations, results in a new conceptual rendering of that

data that results in the theorising outlined in the research findings. The work also contributes to the body of knowledge around methodological considerations when conducting research with children. There is a resultant social and theoretical significance of the work that comes from the presentation of the theorising of the processes the children are engaged in when they are admitted to hospital for surgery. Current practices of caring for children who experience surgery can be therefore be influenced by the findings.

Resonance: The work conceptualises and conveys what is meaningful about the children's experiences from the perspective of children and so makes a contribution to the knowledge that we have of this subject. The categories developed in the analysis portray the experiences of the children around the time of surgery – before, during and after. They have revealed the taken-for-granted meanings of the experience of the children's admission to hospital for surgery and provided the means for these to be considered in terms of the impact they have on children. Further, links have been made with the individual experiences of these children and the wider literature that relates to children's hospitalisation and the recommendations for their care.

Usefulness: The usefulness of a theory relates to the ability for the interpretations to be used in the everyday world. The theorising of this work can be useful to paediatric nursing practice and where children experience hospitalisation, particularly hospitalisation for surgery. The increased understandings that result from the work have the possibility of influencing the care that is provided to hospitalised children, their participation in their care and, more broadly, children's participation in research. The research also provides suggestions for further study that relates to children's hospitalisation and care.

The results of this study offer insights with implications for theory development, paediatric nursing practice and future research with children as discussed below. These insights come not only from the theorising that emerged from the study but also from the process involved in coming to this theorising, through the framing of the study, the interviews, and the process of making meaning of the children's experience.

Methodological contributions

This work has a number of important methodological features that contribute to the knowledge within the discipline of paediatric nursing and to research that involves children as participants. The work extends previous studies in grounded theory with children, and has explored in some detail the methodological fit of a grounded theory approach to research with children aged between 6 and 12 years. Grounded theory has been shown to be ontologically suited to conducting research where children are directly involved as co-constructors.

Child centred research techniques utilised in the study that served to advance knowledge and understandings include the following:

- The utilisation of age appropriate assent documents that allowed children to have control over their involvement in research. Children's assent documents were developed for the study with a group of primary-school age children (Ford et al. 2007) and the process involved in undertaking this kind of activity has not previously been described in the nursing literature. This activity resulted in the development of assent documents that were readily understandable to the children involved in the research. This process has wider potential for the development of documents for children in a variety of contexts. These include for example, other research activities that involve children as participants, and written information for children about hospitalisation as well as specific procedures or conditions.
- Flexible research techniques acknowledge the contribution children can make to the development of nursing knowledge. Flexible techniques supported children and acknowledged and valued their contribution in whatever form they chose. Children chose the level and nature of their participation in the research. They chose whether their parent would be present or not during interview. Flexible techniques allowed for the children's context that included interruptions, noise and variations to interview formats. Such techniques also included use of developmentally appropriate language and questioning that considered the individual child's abilities, experience and cognition. Flexible techniques also allowed incorporation of child centred methods including the draw and write technique.

- Interviewing is not an easy research method to use with children. Practical and ethical problems were a part of this method, and conceptually there were important considerations (Westcott and Littleton 2005). The research details some of the dilemmas encountered when conducting research with children and in doing so adds to the discourse around this area of research with children (Irwin and Johnson 2005, p829).

Implications for practice and further research

Recommendations from this research relate to two main areas:

- Care for children who are hospitalised; and
- Research with children.

Children can and should be involved in their healthcare: The study has highlighted the importance an understanding the child's experience of admission and surgery has for nursing. Some specific aspects of children's experiences of healthcare where their direct involvement is critical include:

1. Effective treatment of children's pain requires that it is essential to have a true appreciation of the child's experience in relation to their pain.
2. Appropriate information for children and their families improves their experience of healthcare.
3. The inclusion of children's perspectives and preferences when planning services for children should be routine.
4. The special healthcare needs of children need to be considered in the care they receive and the environment where that care takes place.
5. Nurses who care for children have an important role as advocates for children and for services appropriate for children.

Children can and should be involved in research: Researching the holistic experience of children's hospitalisation from their perspective has the capacity to provide deeper understandings of the phenomenon from the perspective of those experiencing it.

The research participants were primary school age children who were admitted to hospital for surgery. Children who receive healthcare for other reasons also have a story to tell, including children of different ages and children with chronic conditions; mental health problems and serious illness.

To conclude, this research highlights the special needs of children who are hospitalised and that children require the provision of a safe, child-friendly environment where care is provided by staff specifically trained in caring for children and their families. There is a current social and political shift whereby the healthcare needs of children are being adversely impacted. This research has called attention to the importance of child healthcare that is centred on the needs of children and their families and that includes children as active participants.

Children were active participants in this study and central informants into their own experiences. Constructivist grounded theory is a research method that can provide increased understandings of how children experience their lives and make sense of their world. This study provides a theory of primary school age children's admission to hospital for surgery from the perspective of children themselves.

Appendices

Appendix 1: Sample parent information sheet



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PARENT INFORMATION SHEET (Hospital)

The understandings of primary school age children who undergo surgery

My name is Karen Ford and I am doing a PhD with the School of Nursing, University of Tasmania. My supervisor is Dr Judy Sankey. I am studying primary school age children's experiences of admission to hospital for surgery.

I would like to ask you and your child to participate in this project. The Southern Tasmania Health & Medical Human Research Ethics Committee has given approval for this study.

This information sheet describes what will be involved if you and your child decide to take part in the study. Please take your time to read this information. There is no hurry. Please ask us to explain any words or information that you and your child do not understand.

The study will include about 30 primary school age children who have surgery at the Royal Hobart Hospital, and their parents. Children and parents will take part in a series of interviews where I will ask the children to talk about what it is like going to hospital to have an operation. Drawings by the children will also be used to help gain information from them about their experiences.

When surgery is planned (or elective), the first interview will take place in the days before surgery. When surgery is not planned this interview will not take place. The next interview will be soon after the child is admitted to hospital and the final interview will be after surgery. The interviews will be about 30 minutes long, but this will depend on things like the child's age and their ability to concentrate. Interviews will be in a convenient place, for example in your own home or a room on or near the ward. There is a slight chance that discussing experiences that may have been painful or distressing may cause

further distress. If this happens, follow up counselling will be available to you and your child with the Unit Social Worker.

In the interviews I will ask your child to talk about things like his or her experiences before and after surgery, if there were things that were worrying and what made it easier to deal with these things.

The interviews will be tape recorded. The information from the tapes will be studied to identify important ideas. Finally the findings will be presented in a paper that will be my thesis. The results of this research may also be presented at meetings or in publications; however, your child and his/her identity will not be revealed in those presentations or in my thesis.

Every effort will be made to maintain confidentiality. My records will be stored in a secure place, and my supervisor and I will be the only people with access to the data.

Your participation in the study is entirely voluntary. Written informed consent will be obtained from you and your child. I will not talk to your child about the study until you have given permission. You and your child will be free to withdraw from the study at any time without affecting the care your child receives in any way. You and your child will be given copies of the information sheets and consents to keep.

Who to contact for information about the Study?

Questions regarding the study and your child's participation in the study will be answered by contacting

Researcher: Karen Ford, Paediatric Nurse, Royal Hobart Hospital, 6222 7932.

Supervisor: Dr Judy Sankey, Senior Lecturer, School of Nursing, University of Tasmania, 6324 3398.

If you have questions about your child's rights as a research subject you may contact the: Human Research Ethics Committee (Tasmania)
c/- University of Tasmania
Research & Development Office
Hobart 7001
or call 6226 2763 and ask to speak with a research subject advocate.

If you have any concerns of an ethical nature, or complaints about the manner in which the project is conducted, you may contact the Chair of the Ethics Committee (Dr Helen McArdle) on 6222 8430, or the Executive Officer of the Ethics Committee (Mrs Amanda McAully) on 6226 2763.

Appendix 2: Sample child information sheet

The Information Letter (for children having an operation)

My name is Karen Ford. I am finding out what it is like for primary school children who have an operation.

This letter tells you what will happen if you want to help.

I will interview you. That means I will ask you questions. I will ask you questions like what is it like to have an operation, and what are the good things and what are the bad things.

I will record your voice on a tape. I will also ask you to draw pictures about hospital.

This information will help me write a report that can help other children.

You don't have to do this if you don't want to. If you don't understand anything you can just ask me what I am doing.

I won't use your real name when I write my report. If there is something you don't understand or are scared about you can talk to your parents.

You get to keep a copy of this information letter and the letter that gives your permission.

Thank you for your help.

Karen Ford

Appendix 3: Sample parent consent



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PARENT

CONSENT FOR PARTICIPATION IN A RESEARCH STUDY (Hospital)

The understandings of primary school age children who undergo surgery

Signing this form in no way affects your rights or those of your child. A signed copy of this consent form will be given to you.

The purpose and procedure of the research study have been explained to my child and to me. My child and I volunteer and consent our participation in this research study.

I acknowledge that:

1. I have read and understood the 'Information Sheet' for this study.
2. I understand that the study involves a series of interviews with my child, and that the interviews will be audiotaped.
3. I understand that the results of the study will not be of any direct benefit to my child's medical management.
4. Any questions that I have asked have been answered to my satisfaction.
5. I agree that the information gathered for the study may be published and that my child or I will not be identified as participants.

6. I understand that my child or I may withdraw at any time without affecting the care we receive.

I have explained this study and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

Name of **researcher**

Signature of **researcher** Date

Child's Name

Legal Guardian Signature

Date

Legal Guardian Signature

Date

Legal Guardian (Print Name)

Date

Signature of Person Conducting the
Informed Consent Discussion

Date

Name of Person Conducting the
Informed Consent Discussion (Print Name)

Date

Appendix 4: Sample child assent document

The Letter that Gives Your Permission (for children having an operation)

I have read the information letter with Karen.

I understand what Karen is asking me to do.

I will talk to Karen about what it is like to have an operation.

Karen will record my voice on a tape when I talk to her.

I will draw pictures about hospital.

Karen has answered all my questions.

Karen won't use my real name when she writes the report.

If I don't want to do this I don't have to.

I can stop doing this if I want to.

I get to keep a copy of the Information Letter and the Letter That Gives Permission.

Signature:

Date:

Witness:

Appendix 5: Sample of line-by-line coding of interview transcript

The following excerpts from one interview provides an example of line-by-line coding

Excerpts from Interview Transcript	Coding
<p>K: So are you happy to talk to me about coming to hospital to have your operation? C: Yes... K: What I'm going to ask is you why you came to hospital C: Um because I broke my arm K: You broke your arm. How did you break it? C: I fell off a fence... K: And what happened when you broke your arm? C: It was really disgusting – it was like there and my fingers was like there [indicating the deformity] K: Ok so it was really a different shape... You had to come to hospital. How did you come to hospital? C: My mum drove all the way here K: ...When you realised that you had to come to hospital how did you feel? C: Scared - I was screaming K: And why was that? C: Because I broke my arm K: And how did it feel? C: Nervous</p> <p>K: Was it hurting? C: Yes K: Where was it hurting? C: There [indicates point on forearm].....</p> <p>K: So you came to hospital and what happened when you got to hospital? C: Um mum told a person who works here in the office, on the first floor, and a nurse was seeing if it was all right. And there was a hole about that big and there was blood K: ... And so what happened then? C: Umm.. then I went into a room and a lady gave me some 'blurry' medicine and I was really blurry K: Did that help you? C: Yep K: How did it help you? C: Well I had to breathe really slowly K: So how did that make your arm feel? C: A little bit better K: Ok and then what happened? C: Um... I had to have – my mum went in with me and I had to have my blood- a needle and... um K: You had to have a needle in your hand and why was that C: Mm, don't know K: And what did that feel like having that? C: Scared K: Why was it scary? C: Because I.... don't know</p>	<p>Reason for admission 'I broke my arm'</p> <p>Cause of injury</p> <p>Describing injury 'really disgusting'</p> <p>Coming to hospital</p> <p>Feeling scared 'Scared - I was screaming' Injury a cause of fear</p> <p>Feeling nervous</p> <p>Importance of place: 'on the first floor' Mother's role Nurse's caring role The appearance of the wound was frightening 'a lady' - nurse 'blurry medicine' – pain relief Medicine helped with the pain Understood how to self administer the medicine [inhalation nitrous] Medicine made her feel 'a little bit better' Being with mother 'mum went in with me' Needle Not knowing reason for 'needle' [cannula] 'Scared' of needle 'I don't know' – not knowing</p>

<p>C: I had an operation and then an XRay and they put these metal things in it on Monday, yesterday. And my dad come in yesterday and my mum after my dad. And I had a xray and I had tea...And dad had a little taste of my tea</p> <p>K: What did you have for tea?</p> <p>C: Lasagne, vegies, cauliflower and potato</p> <p>K: And what was it like? Was it good to eat?</p> <p>C: Yep and my dad was tasting it to see what it was.</p> <p>K: Did he think it was alright too?</p> <p>C: Yes and he had another bite and another bite</p> <p>K: Oh he must have been hungry! [laugh]</p> <p>C: Yes and today I went to a school room. And I done some work and [stepmother] and [brothers] came in and then we went in the room and I told [stepmother] something and I had a shower and I smelled nice</p> <p>K: Was it nice to have a shower?</p> <p>C: Yes and [stepmother] is a really good stepmother</p> <p>K: ...Are these your brothers or you step brothers</p> <p>C: My brother and that's my stepbrother and I got another stepsister at an aunty's house and another stepbrother at school</p> <p>C: [asks stepmother] Where would he be right now?</p> <p>[stepmother] at school</p> <p>C: He's older than me</p> <p>K: Ok so there's lots of you!</p> <p>C: Yes</p> <p>K: That's really nice. Can you tell me some of the things that have been good when you've been in hospital?</p> <p>C: They give .. I have to press this button and one of the nurse and doctor always came me</p> <p>K: And what kind of things did they do for you?</p> <p>C: Um they gave me medicine and um.. something to eat</p> <p>K: So that's one of the good things when you needed help someone could come and help you, is that right? What other good things?</p> <p>C: Um. That I get to be in a room with one girl and Mark was in there before, but he left into room 7</p> <p>K: Right and so you were able to make some friends</p> <p>C: Yep! And [brother] made some friends because [brothers] came and played the sony</p> <p>K: Oh right so did you play any of those games?</p> <p>C: No I stayed in bed</p> <p>K: What else was good in hospital?</p> <p>C: Don't know</p> <p>K: What stuff has been hard when you've been in hospital?</p> <p>C: Well.. food when I was trying to eat and walk and get out of bed</p> <p>K: So those things have been hard, moving around and sometimes eating your food is that right?</p> <p>C: Yep</p> <p>K: Because you've only got one hand to use, is that right? So if you had a friend who had to come to hospital, what would you tell them it was like?</p> <p>C: Its really scary on the first day and um.. you have to have an xray and operation and one of my friends came here before, [friend] cause he had the same as me. But he didn't fell off a fence, he jumped off a jetty and he had to have plaster.</p> <p>K: Had [friend] told you what it was like when went to hospital?</p>	<p>'I had an operation'</p> <p>Understanding of surgery</p> <p>Outlining activities over time</p> <p>Parents participating</p> <p>Food choices</p> <p>Liked the food</p> <p>Shared meal with father</p> <p>Use of humour in interview</p> <p>Activity – hospital school work</p> <p>Fun with brothers</p> <p>received assistance to shower</p> <p>Family members</p> <p>The importance of family</p> <p>'Good things'</p> <p>Nurse call bell 'the nurse and doctor always come'</p> <p>Role confusion. Trust in nurse to respond.</p> <p>Role of nurse: Give you medicine, food</p> <p>Enjoyed sharing a room with other children</p> <p>'making friends' with other children. Games and activities</p> <p>Physical activity limited</p> <p>'hard things'</p> <p>Physical limitations, difficulty eating, moving</p> <p>'what would you tell a friend about hospital?'</p> <p>'It's scary on the first day' – lists things that would happen 'script'/'you'</p> <p>Knows a friend who had a similar injury</p>
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<p>C: no</p> <p>K: OK, so there were some good things and there were some bad things. One of the good things was the people that you met and having your family</p> <p>C: Yes</p> <p>K: And why was that important for you</p> <p>C: because they're my family and I love them and all</p> <p>K: And just in case if they weren't able to be here, what would it be like?</p> <p>C: um, sad</p> <p>K: And why is that?</p> <p>C: Because I won't have no-one to look after me and see me, only the nurses and the doctors</p>	<p>Importance of family</p> <p>If they weren't there – would be sad; would not have anyone to look after her or be with her 'only the nurses and the doctors'</p>
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Appendix 6: An example of a code - 'being scared'

Initial coding identified the children's expressions of 'being scared'. The excerpts below indicate text that was coded as 'being scared' from interviews in the early stages of coding. The code 'being scared' was later elevated to a concept.

'Being Scared'

'Because you get scared' (1a)
'Scary' (2b) 'I was happy and scared' (6a)
'I was really scared' (7)
'I felt a bit scared' (2)
'Makes you scared' (3a)
'A bit scared' (4)
'I was a bit scared and spooked about it' (8)
'Scared, I was screaming' (9)
'It was really scary on the first day' (9)
'It felt a bit nerve breaking for me' (10)- from story

Surgery a cause of fear:

'I cried when I was going up there because I didn't want to go up there and have an operation' (2)
'I didn't know whether I would go to sleep or not go to sleep thinking it might not work and I would still be awake' (4)
'Because I'd never had an operation before' (3)
'Because I'd never had an operation or nothing before' (2)
'Because I hadn't had an operation before' (4)
'I was a bit scared about it and they put you to sleep and I woke up in a different room' (5)
'I didn't know if they'd put me to sleep and all that stuff and I thought I wasn't going to wake up' (6a)

Pain as a cause of fear:

'If it was going to hurt me' (3)
[Scared] 'about putting needles in me hands' (4a)
'I was scared when they were putting the drip in' (5a)

Scared of being alone:

'I didn't know if mum would be there and everything' (3)
'Because if she [mother] wasn't here I would be really scared and would wake in the night and be really scared cause I'm scared of the dark' (8)

Causes of the children's 'being scared' included: not knowing what was going to happen; being alone; fear of surgery; pain.

Appendix 7: Memo from one interview

Memo

My first interview with 7 year old Adam (pseudonyms are used) was 5 days following his surgery for appendicectomy and drainage of abscess. On completion of the interview, Adam and his mother both agreed that we could have a follow-up interview at their home following Adam's discharge from hospital.

When I called by phone to make the time for this interview, Adam's mother gave me directions to their house. I had a good idea of the area where the family lived: it is on the outskirts of my own rural community. The landmark Jane identified for the turn-off from the main road was where a public phone box had once been located. It had been removed some time ago. But I knew that place.

When leaving my home I fleetingly considered the appropriateness of my footwear. My Blundstone boots had lost all their shine and were quite white with plaster dust from our home renovations. I (briefly) wondered if I presented the desired image of a researcher with the School of Nursing and Midwifery. But it was getting late, it was very muddy, and I wasn't sure where my other more respectable shoes were.

I checked I had all I needed for the interview, including working recorder and note pad and drove off. I found the turnoff, where the phone box had once stood, and then the next, and began to wind my way along a quiet dirt road. The road began to wind upward, it became narrower and the tall blue gums on either side broached closer. I began to think the house must be soon, and I wished I had pressed the odometer at the road's start because it was beginning to feel like a long way.

But soon I did find the house that was situated close to the road and was greeted by Jane. Jane told me the 4 older children, including Adam, were with their father at their new house site, moving the pigs to a new pen. We went into the house that was warm and cosy from the combustion stove, with the signs of a busy family with young children all around. While we waited for them to return, Jane suggested we share a pot of tea and I nursed the baby, Beth, who was 6 weeks old and Jane put the water on to boil.

We sat down to our tea at the kitchen table, and Jane began to breastfeed Beth as we talked. The warm sunshine was streaming through the window behind Jane and Beth. Soon Beth who was overfull started to spill and it was quite natural for me to fossick through the basket of clean washing beside me for the nappy needed to catch the spilled milk.

After some time sitting and talking, Jane suggested we drive to the block to see what was keeping the other members of the family. Beth was placed safe and secure in her car seat and I climbed into the passenger seat of the big old Landrover. We bumped along the road that became rougher and more potholed and pulled into their block. There was a house site cut into the bush block, a framed house, a couple of sheds, a caravan and stacks of timber milled from the bush. We were greeted by two escaped pigs, the friendly dog Digger, followed by the 4 excited kids and their father. I guessed that my footwear was OK.

I was introduced to all the family members and Adam was initially, but only briefly, a little shy of me. I was invited by the children to see their new house and they excitedly showed me around. They happily answered my questions about where their rooms were to be. I had visions of helping to chase after the escaped pigs, but fortunately that was not required.

Eventually we drove back to the house for the interview with Adam and then lunch. We all kicked off our boots and gumboots at the door, me my now even muddier, Blundstones. Eve, who had already proudly told me she was 3, had sawdust inside her gumboots, and I offered to help her take off her wet, sawdust covered socks before entering the house.

Adam and I conducted the second interview whilst lunch was being prepared.

I have made light of my little adventure. But I have also tried to give a sense of what it was like to enter the field, as it were. Interviewing in the child's own home is a real privilege: to be able to enter into the family's space, and be welcomed by them; to nurse the baby, to be shown up to the loft to see where 6 year old Jess sleeps and to admire Kate's new toys, have a cup of tea, to be invited to share lunch of sandwiches and soup. These aspects of conducting research are not often included in research reports. The human interactions such as those described here were for me most valuable, rewarding and gratifying 30.8.2005.

Appendix 8: Abstract from published work

Journal of Child Health Care

Development of children's assent documents using a child-centred approach

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The call for researchers to obtain children's informed assent, prior to their participation in medical procedures and research, has increased over recent years and parallels moves to implement child-centred approaches to health care. This article describes the processes used to include children in developing a research information sheet and assent form for use in future research into children's understandings of their surgery and hospital experiences. The process involved primary school children aged between six and 12 years. Children worked in small groups to consider information to include in these documents. Their words were collated to construct the research information sheet and assent form. Working with children resulted in documents that were more understandable for their intended audience. The article includes discussion of 'language', 'understandability' and 'readability'; concepts that researchers seeking to work with children need to come to terms with if they are to obtain 'informed assent'.

Key Words: child-centred research • children's assent • ethics

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