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# "VISIBLE-NESS"

## THE NATURE OF COMMUNICATION BETWEEN CHILDREN AND HEALTH PROFESSIONALS IN A SPECIALIST CHILDREN'S HOSPITAL IN THE REPUBLIC OF IRELAND

## AN ETHNOGRAPHIC INQUIRY

**A thesis presented to the University of Dublin, Trinity College for the Degree of Doctor in Philosophy**

**By**

**Veronica Ann Lambert**

***RCN, RGN, BNS (Hons)***

**2009**

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**Drawing by Rachel 9 years (Appendix Mass)**[1]




[1] This is a man and this is his son. He (the man) is going to operate on his son. His son has hurt his leg. They are at home. The man has a scissors, a light on his head and a mask on his face. This is the TV telling the man how to operate. The TV is saying, now you have to place your patient's body to the side and try not to push them off the bed.

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**Title: *"Visible-ness"* The Nature of Communication between Children and Health Professionals in a Specialist Children's Hospital in the Republic of Ireland: An Ethnographic Inquiry.**

## THESIS SUMMARY

**Background:** Although there is evidence of an emerging body of knowledge exploring children's views of their information and communication needs, little is known empirically about the communication process between children and members of the healthcare team in inpatient hospital settings.

**Aim:** The aim of this thesis was to explore and describe the nature of communication for children admitted to a specialist children's hospital setting.

**Methodology:** The principles of ethnography underpinned the design employed. Fieldwork took place in one 35-bed children's ward, in one specialised children's hospital. Forty-nine children, aged six to sixteen years, with a variety of medical and surgical conditions, participated. Multi-modal methods, namely semi-participant observations, unstructured interviews, draw and write technique, stick-a-star quiz and documentary evidence were employed to collect data. All data were recorded in field notes, which were subsequently analysed through grounded theorising; a process of constant dialogical interplay between data, researcher ideas and literature. Two theoretical frameworks, the *circular transactional model of communication* and the principles underpinning the *ecological model of human development* guided the study.

**Findings:** The process of communication for hospitalised children was conceptualised as a *"visible-ness"* construct, with two opposing multi-dimensional extremities, *"being overshadowed"* and *"being at the forefront"*. These two extremities illuminated the degree to which children were, or wanted to be, included, or excluded, in the communication process and the extent to which their agenda was attended to. For instance, at the *"overshadowed"* extremity children were marginal to the communication process. This resulted in their restricted involvement, their voice not being heard, nor their agenda being attended to. Contrastingly, at the *"forefront"* extremity children held a leading position, with health professionals communicating directly with them, or

simultaneously with them and their parents. Although there is the risk that the *"forefront"* extremity would be regarded as the *optimal* position for children to hold in the communication process, this thesis challenges such contentions. The need to appreciate the relevance of **both** the *"overshadowed"* and *"forefront"* extremities in unison, as opposed to **either** extremity in isolation is highlighted. One extremity does not necessarily take precedence over the other because children oscillate between the two extremities depending on a number of factors, namely related to the health professional, child, parent and environment.

**Conclusion:** This thesis offers a unique theoretically integrated contribution to the scant body of knowledge about health professionals' communication practices with children in hospital by presenting a Child Transitional Communication (CTC) Model. This CTC model attempts to explain why health professionals positioned children **either** at the *"overshadowed"* **or** the *"forefront"* extremity of the "visible-ness" continuum. It is proposed that such dualistic positioning of children is representative of the existence of dichotomous thinking, which populates the literature, between the two discourses, protection *versus* participation, both of which are embodied within the extremities *"being overshadowed"* and *"being at the forefront"* respectively. In contrast to health professionals operation of an **either/or** perspective, children preferred an individualised approach to enable them to oscillate back and forth between the *"overshadowed"* and *"forefront"* extremities depending on the context and their needs at that specific point in time. For example, child participants articulated that they simultaneously valued the opportunity to participate in the communication process, in addition to, having the presence and support of their parents during this process. Thus, this thesis challenges the existence and sustainability of contradictory dichotomies/extremities, and **either/or** perspectives, because if health professionals adopt such a bifurcated stance there is the danger that children would be placed in positions which they do not want to assume. The findings reported and discussed within this thesis challenge the simplistic insistence and uncritical political drive for stronger child participation in all matters that affect them, in isolation of debates surrounding children's need for support and protection and any resultant potential negative consequences of children's active participation.

# CHAPTER 1: INTRODUCTION

## 1.0. Background

The last twenty-five years have witnessed a paradigm shift in childhood research. Today, children are recognised as a distinct social group. To understand children and childhood requires exploring children's perspective and participating *with* them in the research process. Central to the vision of the National Children's Strategy, a major Irish Government initiative in its commitment to advance the United Nations Convention on the Rights of the Child, is children's active contribution to society, acknowledging their role as participatory citizens.

This thesis listens to the voices of children as healthcare consumers, with the underlying ethos of the National Health Strategy to accomplish a person-centred health system that *"encourages you to have your say, listens to you, and ensures that your views are taken into account"* (Department of Health and Children, 2001:8 original italics). The recent drive to listen to service users has resulted in the emergence of a body of evidence directly exploring children's views of hospital and healthcare. The dominate theme to emerge from these studies was a lack of communication, thus these studies explicitly accentuate the need for empirical-based evidence on health professionals' communicative practices with children in healthcare.

The United Kingdom's National Service Framework for Children, Young People and Maternity Services states, "staff working with children and young people should have training in the necessary communication skills to enable them to work effectively with children, young people and parents and to support them to be active partners in decision-making" (Department of Health UK, 2003:16). Callery argued that this framework does not present support for such a recommendation because the body of evidence in relation to communicating with children in healthcare is "woefully inadequate" (Callery, 2005:12). While much attention has been attributed to the quality of health professional-adult patient communication, the nature of health professionals' communication with child patients remains ambiguous. This implies that children's nurses have limited

evidence on which to base their work and represents a gap in current knowledge that warrants attention.

### 1.1. Aim

Thus, the aim of this thesis was to explore and describe the nature of communication between children[2] and health professionals in a specialist children's hospital, from children's perspectives.

### 1.2. Objectives

1. To explore the process of communication taking place between health professionals and children in a children's hospital, from children's perspectives.
2. To explore the role of the parent/guardian in the communication process taking place between health professionals and children in a children's hospital, from children's perspectives.
3. To explore the role of the environment in the communication process taking place between health professionals and children in a children's hospital, from children's perspectives.

### 1.3. Thesis Format

This thesis consists of 8 chapters. Following this introductory chapter, *Chapter 2* presents the literature available on the care of children in hospital; in order to contextualise the rationale for choosing the topic under exploration. *Chapter 3* provides an overview of extant communication theories and presents the theoretical frameworks that guided the study. *Chapter 4* outlines the methodology employed in this study. This chapter is presented in three sections: first, the reader is provided with a synopsis of changes that have taken place in the social positioning of children; next, the philosophical and methodological assumptions underpinning this ethnographic inquiry are detailed; and finally the researcher's experience of *doing* ethnography in a children's ward is shared. *Chapter 5* portrays the children's ward where this research was conducted. *Chapter 6*

---

[2] For ease of reading children refers to children and young people, unless otherwise specified.

explicates the nature of communication for hospitalised children by presenting the findings of this thesis. In *Chapter 7,* the implications of the findings are discussed by drawing on six substantive subject areas: childhood sociology; children's rights; adult-child health professional-patient power relations; developmental psychology; philosophy of children's healthcare; and communication theories. *Chapter 8* concludes by presenting a Child Transitional Communication (CTC) Model and advances recommendations for practice, education, research and policy.

# CHAPTER 2: LITERATURE REVIEW

## 2.0. Introduction

Admission to hospital is a potentially traumatic event at every stage and age of development, for both adults and children alike (Erikson, 1963; Sarafino, 2002). Children's incomplete cognition and understanding enhances their vulnerability (DiMatteo and Martin, 2002). Enormous, strange, anonymous and authoritarian places, children often feel lonely, sad, worried, bored and frightened in hospital (Miller, 1979; Hart and Bossert, 1994; Elliott and Watson, 1996; Coyne and Conlon, 2007; Aldiss et al, 2008). Hospitalisation results in children being socialised to become patients with their identity stripped (Beuf, 1989). Separated from the most familiar of places and people, regimented to Martian routines and exposed to many unknown painful procedures; children face many anxieties, with their self-determination jeopardised through imposed helplessness and powerlessness (Vernon et al, 1965; Petrillo and Sanger, 1972; Thompson, 1985; Knafl, Cavallari and Dixon, 1988; Siegel and Hudson, 1992; Wennstrom, Hallberg and Bergh, 2008). To children, hospitals are at once scary places where sick people reside and not so scary when people get better (Carney et al, 2003; Curtis, James and Birch, 2007). Most profoundly, there is a disruption to children's relationships with their family members; the nurse becomes the primary care giver (Darbyshire, 1994). The child meets a multitude of professional caregivers, further exacerbating the complexity of the hospital ward environment (Savage, 2000). The ability to communicate and relate to child patients is valued as principally important in this foreign hospital environment because whether acute/chronic illness, elective/emergency admission, short/long stay, hospitalisation results in a profound lifestyle transition where the child enters an alien world of foreign sights, sounds and smells.

The aim of this thesis was to explore the nature of communication for children in a specialist children's hospital setting. Firstly, by presenting background literature, this chapter hopes to contextualise the rationale for choosing to focus on the topic of communication from the child's perspective. Literature was sourced through numerous channels over the course of this research study, namely, electronic databases (e.g.

CINAHL, MEDLINE (PubMed), PsycINFO, Blackwell Synergy, Academic Search Premier and ERIC), hand and electronic searches of journals, searches of secondary references from selected papers, textbooks, international thesis's, government and other organisation publications, browsing web-sites, e-mailing key personnel and experts in the field of children's research, and attending conferences. The review begins with a brief outline of the development of care for hospitalised children. It then discusses the concept of family-centred care, advocated as the principal philosophy for the care of children in hospital. Following this, the extent to which the voice of the child resonates within healthcare and children's perspectives of hospitalisation are presented, before culminating with the scant, but developing, literature on children's information and communication needs. An outline of background communication theories will follow in chapter three.

### 2.1. Development of Care for Hospitalised Children

Prior to the emergence of hospitals for sick children in the 19th century, dispensary services, which originated in the 1700s, were available (Lansdown, 1996). Dispensaries were where the poor could go for advice and medications. In this epoch, children were invisible and silent with the fear of infection precluding their admission to hospital (Kelleher and Musgrave, 2000). A shift in emphasis occurred in the mid-1800s with the view that it was more advantageous to relocate children to safer healthier dwellings during times of sickness (Kelleher and Musgrave, 2000). Although general hospitals had children's wards, it was gradually realised that children were not miniature adults and that these children's wards in general hospitals were not adequate to cope with sick children (Meenan, 1973). In Ireland, the first hospital exclusively for the care of sick children was established in 1821. Today, three such hospitals exist.

Historically, these hospitals were charitable institutions established to care for sick children of the poor (Meenan, 1973; Kelleher and Musgrave, 2000). For instance, children from overcrowded, unsanitary conditions whose parents worked long hours and had limited facilities, resources and energy to care for their sick children usually required admission (Bradley, 1999). It was common for parents to deliver their child to the care of

the hospital in the belief that it housed the resources, skills and knowledge to care for their sick child. It was the sole responsibility of nurses to follow medical orders and meet the needs of children (Kelleher and Musgrave, 2000). Parents demanding lifestyles and fear of cross infection provided further rationale for excluding parents at this time. Similar sentiments existed right across the globe (Young, 1992). The welfare of hospitalised children did not receive attention until well into the 20th century, over 100 years after the establishment of the first hospitals specifically caring for children. The psychosocial care of children in hospital received much deliberation because of John Bowlby's and James Robertson's work on maternal separation and loss (Belson, 1993; Alsop-Shields and Mohay, 2001; MacDonald, 2001; Lindsay, 2003).

### **2.1.1.** Effects of hospitalisation on children

Prior to the 1980's, short and long-term emotional and behavioural problems occurring during a child's hospital stay and persisting post discharge were reported (Prugh et al, 1953; Vernon et al, 1965; Stacey et al, 1970; Thompson, 1985). The most common child manifestations conveyed were separation anxiety, changes in feeding, sleeping and toilet habit patterns, aggression, irritability, withdrawal, repression, hyperactivity and restlessness (Prugh et al, 1953). While most studies gave an account of negative (emotional and behavioural) outcomes, others relayed a number of positive outcomes (Vernon, Shulman and Foley, 1966; Douglas, 1975). Some studies found no evidence of child disturbances (Davenport and Werry, 1970). The multidimensional nature of children's reactions to hospitalisation was evident. This may be somewhat explained by the large number of variables that were in operation. For instance, children aged 6 months to 4 years, children with repeated hospital admissions, and children with hospital stays longer than 1-2 weeks were thought to be at greater risk of psychological upset (Prugh et al, 1953; Vernon, Shulman and Foley, 1966; Douglas, 1975; Quinton and Rutter, 1976). However, children of older ages also displayed some signs of anxiety, although less frequent and severe (Prugh et al, 1953; Illingworth and Holt, 1955). Poorly adjusted

mothers[3], high maternal anxiety levels, permissive parents[4] (Stacey et al, 1970), chronic family stressors (Douglas, 1975; Quinton and Rutter, 1976), child's pre-admission personality, child parent relationship (Prugh et al, 1953) and degree of stress or specific experience encountered in hospital were other identified vulnerability factors. Ultimately, it was highlighted that numerous variables, including type of illness, could impinge upon the outcomes of all these studies and thus the results were not straightforward or conclusive (Quinton and Rutter, 1976). While, the relevance of this research conducted over 30-50 years ago to modern health services is questionable, these studies illuminate the path that led to the many changes that have occurred in an attempt to safeguard the emotional well-being of children in hospital.

### **2.1.2.** Impetus for change

In recognising the major impact of Bowlby's and Robertson's work and concerned over the effects of hospitalisation on children, the United Kingdom (UK) Ministry of Health set up a committee in 1956 to investigate the welfare of sick children in hospital. The release of the Platt Report acknowledged the emotional and psychological needs of children in hospital and was a major impetus for change internationally (Ministry of Health, 1959; Belson, 1993). Subsequent to this report, there were many attempts to humanise children's hospital experience with many influential UK documents debating the welfare of children in hospital (Department of Health and Social Security, 1976; Department of Health UK, 1991; Audit Commission, 1993; Bristol Royal Infirmary Inquiry, 2001; Department of Health UK, 2003; 2004).

Until recent times, Ireland lagged behind with a dearth of published strategic reports specifically addressing the welfare and needs of children in hospital. The Irish Children's Rights Alliance (CRA) (1997:39), an umbrella body that represents a range of non-government organisations concerned with the rights and welfare of children, recognised this gap recommending the development of standards for child healthcare.

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[3] A poorly adjusted mother refers to a mother who experiences difficulty dealing with her child's repressive and/or demanding behaviour after hospital discharge.

[4] A permissive parent refers to a parent who sets limited rules and regulations for his/her child.

> "A fundamental problem in the health care system is that there are no specific written comprehensive standards or guidelines relating to the provision of health services for children and adolescents. As a result there is no way to measure the consistency, efficacy and suitability of the services available.....The Alliance recommends that guidelines be drawn up which guarantee the rights of children in relation to health and related services and which set down the standards to treatment to which they are entitled."

The Irish National Health Strategy afforded limited space to issues in child health; rather it summoned a review of paediatric services and proposed the preparation of standards in relation to care of children in hospital (Department of Health and Children, 2001). The Health Service Executive/McKinsey Report and Company (2006) and Health Service Executive/Rawlinson, Kelly and Whiltestne Ltd (RKW) (2007) performed this review in terms of building a new National Paediatric Hospital and Network. However, there appears to have been little advancement in relation to preparing standards for caring for hospitalised children;[5] although RKW clearly adopted principles from the English National Service Framework for Hospitalised Children (Department of Health UK, 2003). The perspectives of children were not explored at this initial stage of service planning for a new National Children's Hospital, however, the High Level Framework Brief produced by RKW recommended that children and their parents would be directly consulted with at the next planning stage. The voluntary organisation, Children in Hospital Ireland[6] has played a major role in the development of standards for the quality care of children and adolescents in hospital (Association for Welfare of Children in Hospital Ireland, 1990; Association for Welfare of Children in Hospital Ireland, 1995). Addressing the public at Children in Hospital Ireland's Annual Lecture, in 2007, Mary O'Connor (Chief Executive of Children in Hospital Ireland) advocated for the adoption of the European Association of Children in Hospital (EACH) (2002) Charter for caring for hospitalised children. The EACH Charter sets out cardinal principles, in the form of articles, for caring for children in hospital (Appendix 1).

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[5] Recently, the Office of the Minister for Children (2007) articulated the agenda for children's services in a National Policy document. This agenda provides a means for policy-makers, senior managers and front line practitioners to evaluate their service delivery.

[6] Established in 1970, Children in Hospital Ireland, formerly Association for Welfare of Children in Hospital (AWCH), and its worldwide counterparts have fought hard to raise awareness of hospitalised children's needs.

As articulated within the 10 articles of the EACH Charter, there have been several propositions put forward in an attempt to reduce the potential traumatic effects of hospitalisation on children, namely, unrestricted visiting and parental involvement, adequate preparation, facilities for play and education and care by specialist children's nurses (see Johnson, 1990; Belson, 1993). Here, I concentrate on matters deemed most pertinent to this study because it is beyond the scope of this thesis to comprehensively discuss and review all of these issues. The topic that has received most attention in the literature, as one-way to help ameliorate the adverse effects of childhood hospitalisation, is advocating for a family-centred approach to care.

### 2.2. Family-Centred Care

Today, globally, family-centred care (FCC) is a central tenet and fundamental principle of providing quality care to hospitalised children (Savage and Callery, 2000; Smith, Coleman and Bradshaw, 2002). As Carter (2008:2092) proclaimed, "family-centred care is part of our psyche, part of our professional raison d'être". A core aspect of FCC is the idea that parents/families are extensively involved in caring for their hospitalised child, recognising that the family is constant in the child's life while health professionals are intermittent (Shelton, Jeppson and Johnson, 1987; Smith, Coleman and Bradshaw, 2002; 2006). This was not always the case. Historically, there was no role for parents in the care of sick children in hospital. The contention was that parental presence was *upsetting* to children and that it would be best if they did not visit to allow their child to *settle* (Johnson, 1990; Belson, 1993). A changing attitude emerged in the mid 1900's (Pickerill and Pickerill, 1945; Spence, 1947).[7] The publication of the UK Platt Report (Ministry of Health, 1959) had a slow but eventual international impact on instigating open visiting and living-in facilities for parents to encourage them to have a more active participatory role in their child's care (Connell and Bradley, 2000). Now, there was support for the benefits of unrestricted parental visiting and participation on children's physical, emotional and social well-being (Sainsbury et al, 1986; Cleary et al, 1986; Taylor and O'Connor, 1989). However, despite the well founded benefits, early studies revealed that

[7] The rationale for advocating for mothers to stay with their hospitalised child was not for emotional or psychological reasons, rather for the practical assumption that it would reduce the rates of cross infection.

staff often tolerated parents, rather than actively encouraged them to participate in their child's care. While mothers were allowed to 'live in', they felt captive, under obligation to stay, on trial and uncertain of their role (Meadow, 1969).

### **2.2.1.** What is family-centred care (FCC)?

Socially constructed in its evolution and stemming from the necessity to recognise the importance of the psychosocial needs of hospitalised children, FCC as a pioneering ideology has developed, and advanced, not without its challenges. With the emergence of FCC, a completely new body of terminology has materialised. Terms such as parent presence, involvement, participation, partnership, negotiation, empowerment, family systems nursing, care by parent and FCC are often employed synonymously, interchangeable and with little explanation of their distinguishing features.[8] This is evident in Smith, Coleman and Bradshaw's (2002:22) definition on what FCC encompasses:

> "The professional support of the child and family through a process of involvement, participation and partnership underpinned by empowerment and negotiation."

Many contemplated the emergence and utility of these concepts (involvement, participation, partnership, empowerment and negotiation) differently. For instance, some argued that the terminology changed over time according to its evolutionary status with one concept replacing the previous (Coyne, 1996). For example, it began with parent involvement, progressed to partnership in care and care by parent, before terminating with FCC. Contrastingly, others claimed that a hierarchical relationship existed between involvement, participation, partnership and FCC (Hutchfield, 1999). The base of the pyramid was involvement, a precursor to participation, which in turn is a precursor to partnership, with FCC at the pinnacle.[9] However, while all of these elements are often discussed in isolation of the broader construct of FCC, Smith, Coleman and Bradshaw

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[8] For example, Cleary et al (1986), Sainsbury et al (1986), Casey (1988), Callery and Smith (1991), Palmer (1993), Casey (1995), Coyne (1995a; 1996), Valentine (1998), Hutchfield (1999), Savage (2000)

[9] Others describe different FCC frameworks, functional, hierarchical, holistic and continuous (Smith, Coleman and Bradshaw, 2002; 2006). The continuous frame represents the full spectrum of care, parent involvement, participation, partnership, parent led and non-involvement.

(2002) highlight they are all reflected in contemporary practice FCC, despite whether they are assumed to hold a linear or hierarchical relationship. Regardless of phraseology, or structural representation, the central underlying tenet of FCC, recognised by many, is partnership.

However, this view would appear to be simplistic in its orientation because far from being one-dimensional [sole focus parent participation], FCC is a challenging, dynamic, complex and multifaceted phenomenon around which much ambiguity remains (Newton, 2000; Franck and Callery, 2004). Thus, while the concept of parent participation echoes throughout the philosophy of FCC, the ethos of FCC encompasses far more than merely encouraging parents to actively participate in the their child's care, as portrayed in the following quotations:

> "Family-centred care is a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognised as care recipients" (Shields, Pratt and Hunter, 2006:1318).

> "While it is important to discuss the individual components of family-centered care, it is equally important to consider all the elements as a whole. Family centered care is not just one component. Each element reinforces and facilitates the implementation of others. Together the elements convey a new philosophy of care moving from an institution/agency oriented approach to a child-centered approach and more recently to a family-centered approach" (Shelton, Jeppson and Johnson, 1987:6).

Arguable FCC defies one complete definition. Often it is easier to present its [FCC] core components (Shelton, Jeppson and Johnson, 1987; Johnson, 1990) (Appendix 2). FCC embraces such principles as, respect for child and family, recognition of family diversity, strengths, choices, individuality and involves collaboration, negotiation, communication with, and empowerment of, child and family (Shelton, Jeppson and Johnson, 1987; Johnson, 1990; Hutchfield, 1999; American Academy of Pediatrics, 2003; Franck and Callery, 2004).

### **2.2.2.** Parent presence and participation in family-centred care (FCC)

The drive for FCC and active parent participation led to a wealth of international studies investigating parents and nurses experiences of parent involvement/participation, parent-

nurse relationships/interactions, and parent needs/experiences in caring for their sick child.[10] Collectively, these studies report on the complexities of and challenges faced by parents and nurses in forming partnerships to care for hospitalised children.[11] They highlight the existence of a theory practice dichotomy where FCC appears to be a theoretical idealistic concept and not a practical reality (Darbyshire, 1994; Baker, 1995; Letourneau and Elliott, 1996; Bruce and Ritchie, 1997; Bruce et al, 2002). Is it that FCC is too romantic a notion or that lack of transparency about what FCC incorporates makes it difficult to implement in practice? One explanation for the failure to move beyond the mere mission status of FCC is that its implementation requires a profound shift in institutional and agency culture at countless levels (Shelton, Jeppson and Johnson, 1987; Ahmann and Johnson, 2001). MacKean, Thurston and Scott (2005) declare that the increased vigilance attributed to enhancing parent empowerment and responsibility for caring for their hospitalised child has lost its focus. This is the development of true collaborative relationships between families and health professionals. The *collaborative* facet has vanished with the devolution of *responsibility* to parents.

For collaboration to occur there must be effective two-, or multi-, way communication (Henneman, Lee and Cogen, 1995). Underpinning all the aforementioned studies and emergent themes was the centrality, lack of, or need for more effective communication processes. Communication has been deemed the most important link in the chain to a parent's supportive and successful hospital experience (Shields and King, 2001a&b; Roden, 2005; MacKean, Thurston and Scott, 2005; Young et al, 2006; Lam, Chang and Morrissey, 2006; Avis and Reardon, 2008). For instance, parents reported doctors talking

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[10] (Brown and Ritchie, 1989; Darbyshire, 1994; Evan, 1994; Coyne, 1995b; Kristjansdottir, 1995; Kawik, 1996; Neill, 1996a&b; Callery and Luker, 1996; Callery, 1997a&b; Kristensson-Hallstrom and Elander, 1997; Soderback, 1999; de Lima, 2001; Simons, Franck and Roberson, 2001; Shields and King, 2001a&b; Hallstrom, Runeson and Elander, 2002a&b; Darbyshire, 2003; Espezel and Canam, 2003; Thompson, Hupcey and Clark, 2003; Shields, Kristensson-Hallstrom and O'Callaghan, 2003; Shields, Hunter and Hall, 2004; Fitzgerald, 2004; Buford, [2004] 2005; Kirk, Glendinning and Callery, 2005; Roden, 2005; MacKean, Thurston and Scott, 2005; Tourigny, Chapados and Pineault, 2005; Paliedelis et al, 2005; Ygge, Lindholm and Arnetz, 2006; Lam, Chang and Morrissey, 2006; Young et al, 2006a&b; Shields, Pratt and Hunter, 2006; Soderback and Christensson, 2007; Coyne and Crowley, 2007; Avis and Reardon, 2008; Shields, Young and McCann, 2008; Coyne, 2008)

[11] There have also been a number of literature reviews published in an attempt to assemble a knowledge base on parent participation (see Coyne, 1995a; Savage and Callery, 2000; Corlett and Twycross, 2006; Shields, Pratt and Hunter, 2006; Shields et al, 2007; Power and Franck, 2008).

down to them and receiving inadequate information especially from nurses (Roden, 2005; Lam, Chang and Morrissey, 2006; Coyne and Crowley, 2007). Nurses believed that it was the doctors' role to relay verbal reports to parents, not them (Roden, 2005). While parents supported this view, they felt nurses should inform them about their child's most up to date results, care provided, progress and act as a communication conduit between medical staff, parents and children (Espezel and Canam, 2003; Paliedelis et al, 2005; Lam, Chang and Morrissey, 2006). Darbyshire (2003) reported that mothers valued when nurses *took time out* from the *real* work to interact with and inform them. Darbyshire contended that this conveyed an unhelpful message to parents about what was more or less important in their child's care.[12]

When little negotiation takes place between staff and parents, regarding their role, it leads to different expectations, role conflict and adversarial relationships (Hayes and Knox, 1984; Darbyshire, 1994; Coyne, 1995b; Neill, 1996a&b; Kawik, 1996; Savage and Callery, 2000). There is the risk that parents transmit their stress and anxiety, arising from conflicting roles, to their child, rendering them vulnerable to the effects of hospitalisation (Dearmun, 1994/1995; Coyne, 1995b; Edwinson-Mansson and Dykes, 2004). Both Callery and Smith (1991) and Darbyshire (1994) identified that the balance of power in the nurse parent relationship weighs in the nurse's favour. Children's nurses allege that the hospital's organisational structure, in relation to power roles and rules, influences their behaviour, nursing care and relationships with parents (Brown and Ritchie, 1989). Another factor which could potentially affect the process of communication between parents and health professionals is the perception of who owns the child in hospital (Noyes, 2000; Shields et al, 2003; Lewis et al, 2007).[13] If contemporary nursing advocates for children's nurses to work in partnership with families, power must dissolve. One way for nurses to liquefy this power is to share and provide information and be open in their communication with parents (Hallstrom, Runeson and Elander, 2002a;

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[12] Parents' reluctance to participate in their child's care could be an attempt to increase staff communication time (Coyne, 1996) and attention to children (Avis and Reardon, 2008), with parent participation resulting in superficial contact with numerous staff (Kristensson-Hallstrom and Nilstun, 1997).

[13] Noyes (2000) reported that young people, and their parents, perceived nurses assumed ownership of them. Parents in Lewis et al's (2007) study relayed similar thoughts.

Henderson, 2003); a component deemed integral to effective FCC (Shelton, Jeppson and Johnson, 1987).

Yet, there is limited empirically derived knowledge on the *effectiveness* of FCC [parent participation] for hospitalised children (Shields, Pratt and Hunter, 2006; Shields et al, 2007; Carter, 2008; Shields and Hunter, 2008). As Carter (2008:2092) commented, "we could view the mountain of articles as evidence that family-centred care is a failed experiment; something we have tried but which clearly does not actually work". One attribution to the difficulty of effective evaluation of FCC, in terms of improved outcomes for families, and more substantially for the child patient him or herself, as postulated by Corlett and Twycross (2006), could be its ill-defined nature. In spite of this, and important for the context of this study, parental presence is frequently reported as essential for health professionals to communicate with children. Parents were often regarded as a *bridge* or *communication conduit* between health professionals and children (deemed fearful of health professionals and injections) (Knafl, Cavallari and Dixon, 1988; Buford, 2005; Lam, Chang and Morrissey, 2006; Soderback and Christensson, 2007). Moreover, health professionals relied on parents to communicate with children. Yet, parents valued not only when health professionals communicated directly with them but also with their child (Knafl et al, 1992; Buford, 2005; MacKean Thurston and Scott, 2005). Mothers in Darbyshire's (2003) study were in no doubt that health professionals directly informing and involving their child benefited later in their child's post-operative recovery period. Similarly, in Wollin et al's (2004) study parents felt time spent by doctors and nurses talking to children helped reduce their child's anxiety. Contrastingly, other parents did not want communication to take place in earshot of their child because it could potentially cause him/her anxiety (Evan, 1994). One explanation could be the different time-periods of these studies, just about 10 years apart, within which society has witnessed monumental changes about involving children in all matters that affect them.

### **2.2.3.** Child presence and participation in family-centred care (FCC)

While there are distinct advantages of having open parental access and living-in facilities for parents, literature has largely focused on parents and health professionals'

perceptions, expectations, roles and responsibilities; nature of negotiation and issues of power and control in relation to the concepts of parent participation and FCC (Paliadelis et al, 2005; Shields, Pratt and Hunter, 2006; Corlett and Twycross, 2006; Young et al, 2006a&b; Ygge, Lindholm and Arnetz, 2006). One overarching omission across this body of research has been the absence of the voice of the child (Savage and Callery, 2000; Corlett and Tywcross, 2006; Shields, Young and McCann, 2008). The omission of the child's voice is apparent in the following quote from Bradshaw and Coleman (2007:35) where they state that the introduction of FCC stemmed from the recognition that: "children have different needs to adults and children's nurses and parents of sick children would benefit the sick child by working in partnership".[14] Furthermore, Bradshaw and Coleman (2007:39) describe FCC as a two way process existing between the parent and health professional and "when this expertise is harnessed together it can be a powerful force for the good of the sick child because it leads to the two-way sharing of helpful information and skills". Within this view, both nurse and parent are experts, the nurse an expert in nursing and the parent an expert on their child. Where does the child sit within this partnership? What is the child's role?

There appears to have been a shift from focusing on the psychosocial needs of children to the needs of their parents. While children's needs remain the driving force for health professionals and families to establish and maintain relationships, Dickinson, Smythe and Spence (2006) highlighted that the child is more of a *presence* rather than *present* in health professional-family relationships. Within this perfusion of literature there is limited empirically derived knowledge focusing on communication as it relates to members of the healthcare team and children specifically (Callery, 2005). Coyne and Crowley (2007) acknowledge this deficit of investigating the child's voice and contend that an explanation for overlooking children's autonomy and self-determination is the use of the term partnership, which implies a dual relationship. This might be one interpretation. However, a definition of partnership is "an association of two or more people as partners" (Soanes, Spooner and Hawker, 2001:644). Another explanation could

[14] Also highlighted in key reports such as the Platt (Ministry of Health, 1959) and Court Reports (Department of Health and Social Security, 1976)

be the challenge of ensuring the voice of the child is heard when parents interrupt their child's story, interpret meanings and/or correct their child's story (Dickinson, Smythe and Spence, 2006).

As a consequence of the absence of the voice of the child, the position the child assumes within the context of FCC has not been explicitly stated or explored. Rather, the focus tends to be on parent participation and partnership. For example, Ahmann (1994:113) stated "the philosophy of family-centred care calls for partnerships between parents and professionals – partnerships that support parents in their central caring role". This definition implies that FCC is an approach that supports parents in their care-giving role through the establishment of parent health professional partnerships. This parental focus is also clearly evident in the early definition and defining principles of FCC advocated by the Association Care of Children's Health (ACCH) and Institution for Family Centred Care (IFCC) in the USA. For example, the definition and defining principles refer to "parents and professionals as equal in a partnership", "parent/professional collaboration" and "sharing of unbiased and complete information with parents about their child's care" (Shelton, Jeppson and Johnson, 1987) (see Appendix 2).

One strong point of Smith, Coleman and Bradshaw (2002:22) contemporary definition, of FCC, is that it stresses the importance of supporting and involving both 'child' and 'family' throughout the care delivery process:

> "An overarching contemporary definition of family-centred care could therefore be seen as: The professional support of the child and family through a process of involvement, participation and partnership underpinned by empowerment and negotiation."

In spite of this, limited referral was made to the child in the context of the Practice Continuum Tool proposed by Smith, Coleman and Bradshaw (2002); albeit covertly assumed to be included within it (Smith, Coleman and Bradshaw, 2002; 2006; Bradshaw and Coleman, 2007). Although both Mountain (2002) and Bradshaw and Coleman (2007)

did refer to both child and family[15], it would appear to be tokenistic involvement of the child. Apart from highlighting the need to incorporate the "developmental needs of infants, children and adolescents" into healthcare delivery systems, the position of the child within this parent professional partnership and concept of FCC is not explicitly accentuated (Shelton, Jeppson and Johnson, 1987). Indeed, while the suggestion is to take account of children's developmental needs, guidance on how to do this is not forthcoming.

One possible explanation for the omission/implicit concealment of the child could be the potential recognition of the child as being part of the family, with several authors failing to define overtly what they mean by family. For example, MacKean, Thurston and Scott (2005:75) referred to the family as "whenever the term family is used we are operationally defining it as the child and their family". Galvin et al (2000) operationally defined the family as the "parent(s), children, and significant others" and Mountain (2002: 62) states the family is often read as "parents". While Bradshaw (2002) and Smith, Coleman and Bradshaw (2006) do highlight the variability within how the term family is defined, mainly as a result of social norms and societal changes, they fail to define family or indeed the position of the child within the context of the family and the FCC practice continuum. Nevertheless, Bradshaw and Coleman (2007:48) recommended giving some thought to the question, what is a family, within the context of FCC. They offer six sub-types of the concept family.[16] In considering the family as a unit of care, Hemphill and Dearmun (2006:19) contended:

> "Families take many diverse forms and are open to many interpretations. In essence, the family is who it identifies itself to be, and therefore a family assessment should start by asking the family 'who is in this family?"

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[15] Mountain (2002:75) stated the "concept of parent participation can be seen to have evolved to embrace working partnerships with not only parents but also relatives and more importantly children themselves." Bradshaw and Coleman (2007:40) relayed that "it is acknowledged that children are capable of and may choose to lead their own care in some instances."

[16] Six different types of families as identified by Bradshaw and Coleman (2007:48) are *nuclear family* consisting of mother, father and child/children; *extended family* is a nuclear family plus other relatives of either or both spouses/partners that live together; *patriarchal family* where the man has the main authority and decision-making power; *matriarchal family* which has the woman as the main authority; *reconstituted family* consists of one divorced and one widowed adult with his/her children and a new spouse/partner with his/her children; *lone/single parent families* which consist of one adult living with his/her child/children.

Franck and Callery (2004:266) further illustrated the diversity inherent within the conceptualisation of the term family.

> "The term 'family' can be used broadly to refer to the social environment, within which parenting is conducted. 'Family' is therefore used to describe a range of social relations, without assumptions either about conformity to social norms or of value: families can include arrangements that differ from traditional notions of two adults of different sexes and their children, and it is possible for families to be dangerous as well as benign environments."

Interestingly, in 1988, when first conceptualising a partnership approach as a model of care for hospitalised children, Casey accentuated a process of nursing that would be carried out in partnership with the child and his/her family. Despite defining the family as parents and significant others,[17] Casey (1988:8) recognised the child as a unique entity with the potential ability to participate in his/her own care:

> "The child is a unique entity; a developing human being who has rights in law. Because he is immature, his rights may differ from those of adults. The child is functioning, growing and developing – physically, emotionally, socially, intellectually and spiritually. In order to do this he needs care in the form of protection, sustenance, stimulation and love."

The above extract captures a number of key issues, firstly it recognises the child as a unique entity and secondly it acknowledges that while the child has distinct rights it also appreciates that because of his/her immaturity the child is also in need of protection and support as he/she develops. Perhaps what is happening here and ultimately resulting in much confusion is the juxtaposition of 'child centred' and 'family centred' care. Franck and Callery (2004:269) illuminated this tension between child and family interests stating:

> "The difference between 'child-centred' and 'family–centred' care is one of emphasis: neither term can exclude the other, because child centred care must take account of the social environment in which children live and FCC must be primarily concerned with health of children."

Franck and Callery (2004) acknowledged, however, that children and families may have differing objectives, preferences and perspectives and in some cases, children may be in

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[17] Casey (1988:8) referred to the *family* as "family is taken to mean parents and others who significantly influence the continuing care of the child – ie the group which takes responsibility for meeting the child's needs".

the best position to assert their own perspectives. Although, Coleman (2007:350) argued that:

> "Child centred care seems to be about adults doing things in the child's best interests and protecting them as opposed to listening to them and assisting them to develop competency and autonomy."

Thus, while the UNCRC (1989) stresses the importance of listening to children, as previously highlighted, how these rights are interpreted are influenced by how adults perceive childhood, children's level of competency to participate and what is in the child's best interest (Coleman, 2007). However, limited debate has taken place in relation to children's rights and the social positioning of children within the contexts of FCC. In 2004, Franck and Callery requested a re-conceptualisation of FCC, and in 2007, Shield et al pleaded for more stringent quantitative examination of the use of FCC as a model for care delivery to children and families in health services. In 2008, Carter (2008:2093) recommended:

> "Stop and take notice of the elephant [FCC]; problematise it and start to understand it. Only then do I think it will be worth doing what Shields et al (2006) and many others have called for, which is 'more research.....to ensure that it is being implemented correctly.'"

Carter (2008) argued that we – practitioners/academics/educationalists – have failed to engage adequately in critical debates surrounding the philosophy of family-centred care. Perhaps what has happened is as Darbyshire (1995:31) contended over ten years ago:

> "The concept of family-centred care is such a cherished tenet of paediatric nursing to be almost above critique. Yet a close examination of the place and meaning-in-practice of family-centred care is long overdue if the term is not to lapse into mere cliché or slogan."

To this, I would like to add my admonition to the extensive body of evidence that exists on the notion of FCC. This is that the literature has largely focused on parents and health professionals' perspectives of the concepts of parent participation and FCC. What is missing here is the voice of the child. This is further advocated here, especially in relation the position, role, expectations and views of the child patient, not only in terms of the role of their parents in their care, but also in relation to the child's own participation. Despite the strong discourse outside healthcare, both nationally and internationally of children's

participation, child participation in the context of FCC is a neglected concept. Within medical care, the American Academy of Pediatrics (2003:694) has suggested:

> "Paediatricians should promote the active participation of all children in the management and direction of their own health care, beginning at an early age and continuing into adult health care."

We need to hear the voice of the child within the FCC framework which to date has been omitted. This point was also emphasised by Sydnor-Greenberg and Dokken (2001:225):

> "In any discussion on pediatrics or family centered care, it is imperative to remember that children are first and foremost the patients. Any interaction with healthcare professionals occurs with families and children.....in pediatric and family-centered care, children are important, even essential, partners in communication."

The above quotation highlights the need to re-examine the positioning of the child not only within the context of FCC but also within the communication process. In their study, in addition to investigating parents and health professionals' views on parent participation, Coyne and Crowley (2007) did attempt to examine child-patient views. Unfortunately, the dominant voice of the adults prevailed in their paper with children's views presented integrated into parent and nurses perspectives (Coyne and Crowley, 2007). In their work on exploring the needs of parents of hospitalised children, Shields, Kristensson-Hallstrom and O'Callaghan (2003) and Shields, Young and McCann (2008) suggested future research to explore children's views. How can we effectively shape services for this particular population of hospitalised children and claim to be responsive to their user needs without eliciting their views? Pyorala (2004) advocated for children's visibility in healthcare. This is essential because as illustrated previously FCC encompasses far more than merely parent presence, involvement and participation. It is a holistic family perspective, which includes both children themselves and their parents as active partners engaging with health professionals in care, treatment and decision-making.

### 2.3. Children's Views of Hospitalisation and Healthcare

The recent drive towards consumerism and listening to service users has resulted in a vast outpouring of a body of evidence directly exploring children's views of hospital and

health care.[18] These studies adopted a wide variety of flexible approaches, ranging from interviews, questionnaires to observations, some with the incorporation of an assortment of participatory techniques. Children across a wide age span and with a broad range of both acute and chronic illnesses participated. Although there was great variability in sample sizes, most tended to be small (less than 20 participants). The timing and location of data collection also varied across the studies, from pre-admission, to time of admission, to post-admission. Owing to the variety of methodologies employed across a wide range of age groups, in many different settings, it is difficult to draw comparative conclusions. Nonetheless, these studies capture valuable insights into children's perspectives with a number of common threads emerging, notably, parental presence, physical and social environmental factors, friendly health professionals, treatment issues and lack of communication.

### **2.3.1.** Parental presence

Section 2.2 outlined the importance of the family as constant in the child's life and the plethora of empirical studies focusing on parent participation in their child's care. Here, children, of all ages, further highlighted the importance of having their parents present with them during their hospitalisation (Horstman and Bradding, 2002; Carney et al, 2003; Pelander and Leino-Kilpi, 2004; Gibson et al, 2005; Coyne, 2006; Lewis et al, 2007; Clift, Dampier and Timmons, 2007; Aldiss et al, 2008). Children valued the presence of their parents for a number of reasons, mainly, to help relieve their fear, to provide them with companionship, to help with their daily activities and to act as a communication mediator between themselves and nursing staff (Pelander and Leino-Kilpi, 2004; Gibson et al, 2005; Lewis et al, 2007). Children hated been separated from home with disruption to their usual routine of being with their family, going to school and playing games with friends (Sartain, Clarke and Heyman, 2000; Carney et al, 2003; Pelander and Leino-Kilpi,

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[18] For example, Elliot and Watson (1996), Chapman et al (2000), Noyes (2000), Sartain, Clarke and Heyman (2000), Sartain et al (2001), Runeson (2002), Cross and Gregory (2002), Horstman and Bradding (2002), Carney et al (2003), Battrick and Glasper (2004), Pelander and Leino-Kilpi (2004), Curtis et al (2004), Board (2005), Gibson et al (2005), Coyne (2006), McDonald and Rushforth (2006), Bray (2007a), Clift, Dampier and Timmons (2007), Lewis et al (2007), Coyne and Conlon (2007), Curtis, James and Birch (2007), Wennstrom, Hallberg and Berg (2008) and Hutton (2008).

2004; Gibson et al, 2005; Coyne, 2006; Clift, Dampier and Timmons, 2007; Wennstrom, Hallberg and Berg, 2008). While children with chronic illnesses and adolescents were adept at creating their own niche in hospital (Sartain, Clarke and Heyman, 2000; Gibson et al, 2005; Hutton 2008), regardless of previous hospital experiences, children continued to fear the unfamiliarity of this environment and health professionals (Coyne, 2006; Coyne and Conlon, 2007).

### 2.3.2. Physical and social environment factors

In terms of the physical environment common dislikes that children of all ages reported were, noise, bright lights (especially at night), heat, food, inadequate play facilities or schooling and nothing to do (Noyes, 2000; Heary, 2001; Horstman and Bradding, 2002; Carney et al, 2003; Coyne, 2006; Clift, Dampier and Timmons, 2007; Curtis, James and Birch, 2007). Children of all ages wanted hospital to be a fun place and liked the hospital setting when they made friends and were engaged in play activities and school (Elliott and Watson, 1996; Heary, 2001; Sartain et al, 2001; Horstman and Bradding, 2002; Pelander and Leino-Kilpi, 2004; Curtis et al, 2004; Gibson et al, 2005; Aldiss et al, 2008). These findings are not surprising considering the heart of every healthy child's lifestyle is playing and schooling, both recommended as an integral part of children's hospital stay (Ministry of Health, 1956; Department of Health UK, 1991; Association for Welfare of Children in Hospital Ireland, 1993; Webster, 2000; Office of Minister for Children, 2004). Yet, young people frequently reported that hospital environments did not meet their needs.[19] Young people felt inconvenienced sharing with noisy younger children, with their privacy compromised (Battrick and Glasper, 2004; Gibson et al, 2005; Bray, 2007a; Coyne and Conlon, 2007; Curtis, James and Birch, 2007). One of young people's most negative experiences of hospitalisation was lack of peer support and interaction (Clift, Dampier and Timmons, 2007). This resulted in them feeling anxious, isolated, bored and unhappy. Young people cited social elements, such as making friends with other children, talking to other children in nearby beds, being in the playroom where

[19] For example, Russell-Johnson (2000), Haines and Johnston (2001), Sharma and Finlay (2003), Carney et al (2003), Curtis et al (2004), Salter and Stallard (2004), Gibson et al (2005), Kilkelly and Donnelly (2006), Clift, Dampier and Timmons (2007), Curtis, James and Birch (2007) and Hutton (2008).

they could talk to and get to know other young people, as the best things about the ward (Curtis, James and Birch, 2007). Additionally, friendly and sociable interactions with nursing staff helped young people feel less isolated.

### 2.3.3. Friendly health professionals

Children talked about befriending a doctor or nurse (Elliott and Watson, 1996) and viewed interacting with health professionals as fun. It provided comfort, a familiar face and helped to reduce feelings of loneliness, fear and boredom (Elliott and Watson, 1996; Horstman and Bradding, 2002). There was a clear understanding of the difference in the roles of doctors and nurses. However, there was a distinct perception of a hierarchy related to these roles (Davies-Jones, 1998; Elliott and Watson, 1996; Holyoake, 1999). Doctors were viewed as the technical experts who cured, whereas nurses were the carers and looked after children's general well-being (Carney et al, 2003; Pelander and Leino-Kilpi, 2004; McDonald and Rushforth, 2006). Children liked having the same nurse all the time as it enabled them to build rapport and get to know the staff (Elliott and Watson, 1996; Curtis et al, 2004). In other studies, younger aged children felt that doctors and nurses remained in the background and did not talk to or play with them (Aldiss et al, 2008), whereas older children spoke a lot more about doctors and nurses (Gibson et al, 2005). Children expected nurses to be humane, nice, kind, friendly, helpful, reassuring, honest and non-manipulative (Carney et al, 2003; Pelander and Leino-Kilpi, 2004; Clift, Dampier and Timmons, 2007).

### 2.3.4. Treatment issues

Children frequently identified procedures, pain, operations, injections, anaesthesia and surgery as a source of extreme anxiety and often the worst things about hospital (Davies-Jones, 1995; Horstman and Bradding, 2002; Clift, Dampier and Timmons, 2007; Coyne and Conlon, 2007). Children disliked the physical manipulation, pain and intrusion or invasiveness of having things done to them (Elliott and Watson, 1996; Coyne, 2006). In some studies, children spoke very little about their illness or treatment suggesting that this was not the most important feature of their hospital stay (Carney et al, 2003; Board, 2005; Aldiss et al, 2008). Perhaps one explanation for this is that children wanted to be

seen as a person beyond their illness (Sydnor-Greenberg and Dokken, 2001). Other factors that might explain this finding are children's reluctance to reveal or inability to describe their experiences in order to remain strong and adequately cope with any distress. Some studies specifically investigated children's coping mechanisms to try to understand how children deal with potential stressors associated with their illness, injury, medical treatment and hospitalisation (Stevens, 1989; Bossert, 1994; Thompson, 1994; Spirito, Stark and Tyc, 1994; Boyd and Hunsberger, 1998; Board, 2005).[20] Healthcare personnel who were supportive, gentle, patient, cheerful, who communicated openly, provided privacy, granted control, gave competent physical care and maintained a sense of humour helped to ease the stressors of hospitalisation for these children. Furthermore, familiarity with staff and increased information helped to alleviate distress, fear of the unknown and uncertainty. These findings suggest that effective communication might, in some way, enhance children's ability to cope with their hospital experience. While a wealth of valuable data emerged from these studies, there was one core consistent finding, *communication*, or lack of it.

### **2.3.5.** Lack of communication

Lack of communication was a major concern for hospitalised children of all ages. The most common themes to emerge from a gross anthology of feedback from children about healthcare were communication, information and involvement (Boylan, 2004; Odigwe, 2004). Children wanted information (clear, honest, accurate and unambiguous), involvement, consultation and to be listened to (Chapman et al, 2000; Horstman and Bradding, 2002; Garth and Aroni, 2003; Curtis et al, 2004; Kelsey and Abelson-Mitchell, 2007). In Buford's (2005) American study, children (8-13 years) expected information to come from doctors and nurses, although they relied on their parents to interpret it for them. In England, Gibson et al (2005), in exploring children's views on their care and support needs during and after oncology treatment, reported differences in who acted as the primary informer for younger and older children. Whereas older children wanted health professionals to speak with and inform them directly, younger children did not

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[20] See Melnyk (2000) for a review of sources of hospital stressors, factors influencing adjustment and interventions to enhance coping outcomes for children and parents.

recall health professionals giving them information but rather talked about their parents informing them about their illness and treatment. There were also differences in the amount and type of information children wanted. Some children felt that they had received insufficient information, whereas others found too much information overwhelming and upsetting (Garth and Aroni, 2003; Gibson et al, 2005; Wennstrom, Hallberg and Bergh, 2008). This highlights the need for information individualisation. Children experience extreme anxiety and apprehension when admitted to hospital. Their fears often relate to the unknown as they try to interpret what is wrong, why they feel unwell and what will happen while they are in hospital (Clift, Dampier and Timmons, 2007; Coyne and Conlon, 2007; Wennstrom, Hallberg and Bergh, 2008). Communicating with and providing a hospitalised child with adequate information is crucial to alleviate these fears and anxieties.

### 2.4. Communicating with Children in Healthcare

The greatest political drive towards listening to the voice of children and increasing their participation has stemmed internationally from the United Nations Convention on the Rights of the Child (UNCRC) (United Nations, 1989).[21] The UNCRC outlines children's basic human rights, categorised under the headings, protection, participation, provision and prevention (Marshall, 1997; Burr and Montgomery, 2003; Hill et al, 2004; Sinclair, 2004). As a direct result of this convention, recent years have witnessed a discernible movement towards children's participation in service design, delivery and evaluation, at both an individual and collective level, with the current drive to develop cultures of participation.[22] The National Children's Office (NCO), Children's Rights Alliance (CRA) and National Youth Council of Ireland (NYCI) (2005) presented a wealth of examples of

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[21] New paradigms in social science were also influential in this shift towards increasing children's participation, recognising children as social actors, who actively play a role in shaping their environment (Sinclair, 2004).

[22] For example, Fajerman and Treseder (2000), Kernohan (2002), Lightfoot and Sloper (2002), Kirby et al (2003), Coad and Lewis (2004), Hill et al (2004), NCO, CRA and NYCI (2005), Coad and Houston (2006), Action for Sick Children (2006) and the Office of the Minister for Children (2007).

participatory work in progress throughout Ireland.[23] This work has stemmed from Ireland's ratification[24] to the UNCRC in 1992, whereby the Irish government instigated a number of initiatives nationally to progress the United Nations (1989) global recommendations for socially including children. Most notable were, the establishment of a National Children's Office (now integrated into the Office of the Minister for Children and Youth Affairs), the publication of a National Children's Strategy and the appointment of a Children's Ombudsman (Department of Health and Children, 2000); with the government recently investing €12.3 billion in children in the National Development Plan (Government of Ireland, 2007). In line with Article 12 of the UNCRC, the first goal of the National Children's Strategy is to ensure that children's voices will be given due weight, in accordance with their age and maturity, about matters that affect them (Department of Health and Children, 2000).

### **2.4.1.** Children's involvement in consultation and decision-making

An essential aspect of quality child-centred healthcare is enabling children to participate in healthcare consultations and decisions that affect them (European Association for Children in Hospital, 2002; Department of Health UK, 2003; Health Service Executive/RKW, 2007). While health professionals often believe they involve children in their care (Simons, Franck and Roberson, 2001), there is still evidence within healthcare provision that children do not have their civil rights and freedom respected (Noyes, 2000).

A number of studies have focused on health professional-parent-child triads in an attempt to describe interactions at general practitioner (GP) and outpatient consultations (Strong, 1979; Pantell et al, 1982; Silverman, 1987; Inman, 1991; Meeuwesen and Kaptein, 1996; vanDulmen, 1998; Tates et al, 2002; Savage, 2003; Savage and Callery, 2005; 2007). Key themes to emerge from these studies were that consultations were mainly dyadic exchanges between parents and health professionals. Children, of various ages, remained

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[23] The Cootehill and Ballybay Adolescent Friendly Health Project provided an exemplary example of participatory work by children and young people (Johnson, Fitzpatrick and McMenamin, 2005).
[24] Ratification refers to a nation's agreement to be legally bound by the terms of the Convention (Mohr and Kennedy, 2001)

marginalised, resulting in their social exclusion. VanDulmen (1998) reported that children's (mean age of 5 years) contribution to outpatient encounters was a mere 4%. Adults (health professionals and parents) played an influential role in enhancing or restricting the level of children's participation in consultation. There was inequity in the way information flowed (Pantell et al, 1982; vanDulmen, 1998). Even children as young as 4-5 years believed that asking questions and giving advice constituted a large part of the doctors' role, whereas patients were mainly involved in disclosing information and regardless of age asked few questions (Haight, Black and DiMatteo, 1985).[25] Focusing on ten children's (5-17 years) views (drawings and taped conversations) of the service provided in an oncology clinic, Inman (1991) found that children focused less on the medical consult itself and more on the waiting period preceding the medical consultation, which centred on playing activities with peers. Inman noted that the doctor dominated the consultation with parents reporting that children were more acceptable of clinic visits when they received personal attention, appropriate and adequate information and were handled sensitively. Meeuwesen and Kaptein (1996) and Tates et al (2002) reported a substantial increase in children's involvement over the years (1970s to 1990s) in all parts of the consultation. The child's increased involvement resulted from the doctor giving the child more space, in addition to, the child taking more initiative. Arguably, the outcomes of the aforementioned studies could be a result of the time-period in which they took place; before the initiative of the UNCRC (1989) and crusade of the new sociology of childhood; which recognises children as active social agents (James, Jenks and Prout, 1998; James and James, 2004). However, this was not always the case (e.g. Savage, 2003; Savage and Callery, 2005; 2007).

Savage's work focused on the role of children in clinic consultations about dietary management in Cystic Fibrosis. She interviewed 32 children (6-14 years) and observed 21 of these children during clinic consultation at two Cystic Fibrosis centers in Ireland. Key themes to emerge were, the marginalised position of children (conversations were primarily directed towards parents), the surveillance approach to consultation

[25] Similar issues are evident in doctors' communication with adult patients (Mishler, 1984; Barry et al, 2001; Maquire and Pitceathly, 2002).

(interrogative questioning style), the privileging of parents accounts (over children's) of children's diet, and the focus on nutritional and medical aspects of the diet (which did not address the child's priority). Similar to other studies (e.g. Meeuwesen and Kaptein, 1996; Tates et al, 2002), Savage and Callery (2007) reported doctors attempts to involve older children (greater than 10 years) in consultations, although these were often stifled by parents. This suggests that age criteria are predominantly influential in assessing children's competence to participate. An influence here may be child development theories such as Piaget's age-stage theory. For instance, studies investigating children's understanding and knowledge of their internal body parts and of health and illness suggest that as children's cognitive ability matures, their conceptions become more sophisticated (Bibace and Walsh, 1980; Brewster, 1982; Eiser and Patterson, 1983; Eiser, Patterson and Eiser, 1983; Chevannes, 1995; Oakley et al, 1995; Hanna, Jacobs and Guthrie, 1995; McEwing, 1996). While these studies are of clinical importance, illustrating the need to consider children's thought processes and perceptions at different ages, drawing solely on age related stages fails to consider the role of experiences and socio-cultural contexts in shaping competencies.

These aforementioned studies merely described patterns of interactions within single medical encounters, at structured GP or outpatient clinics. Perhaps the unstructuredness and uncertainty of collecting data in a busy ever-changing inpatient ward setting is one reason for choosing more structured GP or outpatient settings (Silverman, 1987). Furthermore, the majority of these studies did not explore children's views (exception Haight, Black and DiMatteo (1985), Inman (1991) and the work of Savage), failed to capture interactions with nurses and in inpatient hospital setting. Thus, it is difficult to transfer and apply these findings to inpatient hospital settings where patients experience sporadic interactions within the *hustle and bustle* of a ward setting. One small-scale study (n=10) was sourced which concentrated on consultants' hospital ward round in a hospital inpatient setting, from children's (5-14 years) perspective (using drawings and taped conversations) (Martin, 1994). Children felt scared, terrible, worried, embarrassed, inhibited by numbers (of health professionals on the ward round), pushed into a corner and unable to ask questions. Thus, it is perhaps not surprising that one dominant feature

in children's drawings was the presence of their parents' situated between them and the consultant.

Some Swedish studies have focused on children's participation in decision-making in inpatient clinical settings from parents, children's and health professionals' perspectives (Runeson et al, 2000; Runeson et al, 2002b; Hallstrom and Elander, 2004). These studies revealed that health professionals did not always listen to children's opinions, wishes or valuations, or enable them to participate in decisions. One possible explanation, for not involving children in consultations and decision-making, is their perceived irrationality and socio-cognitive in-competence. While there is often much uncertainty about children's competency (and how to assess it) to make autonomous decisions about their own healthcare, the work of Priscilla Alderson and others has demonstrated that given the opportunity, appropriate explanation and adequate time children can be competent decision-makers (Alderson, 1993; Alderson, Sutcliffe and Curtis, 2006). These authors contended children's competence developed through experiences and relationships. Does this mean that children without experience (of, for example, healthcare) are incompetent to express their view or make decisions about matters that affect them? Kilkelly and Donnelly (2006) felt health professionals might not appreciate the importance of their own role to assist children through effective communication so that they could acquire the necessary level of capacity. How can children become competent in expressing their views and decision-makers without the experience of being involved in making decisions? Runeson et al (2002b) suggested health professionals face an ethical discord between following hospital routine and supporting the voice of the child. Thus, suppressing children's voices could serve as a strategy to simplify ethical challenges.

Another reason for maintaining children's passivity is the recognition that child autonomy, rationality and ability to participate in decision-making conflicts with the desire or need to protect them (Dixon-Woods, Young and Heney, 1999). Are health professionals afraid of being unable to deal with any emotional consequences of upsetting child-patients? Young people themselves recognised the dichotomy inherent within participating in decision-making (Kelsey and Abelson-Mitchell, 2007; Kelsey, Abelson-

Mitchell and Skirton, 2007). Young people simultaneously valued their own involvement and their parents support in making healthcare decisions. There is an inherent battle between autonomy *versus* protection, which contributes to unstable interactions and many challenges for health professionals (Pyorala, 2004). Hence, there is much complexity within the decision to involve, or not, children in the decision-making process with many influential factors,[26] not merely competence and experience.

In an attempt to develop an enhanced understanding of children's involvement in consultation and decision-making in healthcare there are three-key reports, all published in 2006, which I will briefly focus on. Firstly, a literature review conducted in the UK on the involvement of children in decision-making processes in healthcare services (Coad and Houston, 2006). Secondly, two Irish based projects, both commissioned by the Office of Minister for Children after the commencement of this study. One investigated children's experiences of participation in consultation and decision-making in Irish hospitals (Coyne et al, 2006) and the other examined the extent to which children were listened to in Irish healthcare settings (Kilkelly and Donnelly, 2006).

In their review, Coad and Houston (2006) illustratively outlined the extensive range of useful resources for identifying appropriate approaches for engaging with and consulting children. However, any real practical utility of these guides in healthcare was severely lacking. Children were rarely full partners/participants in healthcare services. At both, micro (children's individual involvement in their own care) and macro (children's collective involvement in wider service planning) levels, limited publications were sourced on how children participate in decisions, the extent to which children want to participate in decisions, what children prefer to make decisions about and how best to support children's participation in healthcare. Coad and Houston (2006:21) concluded that "individual CYP's [children and young people's] participation is thus only at a fledging stage with most participatory initiatives being centred on consultations to gather

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[26] For instance, protest from child, child's age, maturity of child, parental role, staff attitudes, time factor, alternative solution to problem (Runeson et al, 2001) and children's best interests, knowledge, values and attitudes, roles and partnerships, power, and economy (Hallstrom and Elander, 2005).

views and experiences". To date, the focus has been on the involvement process as opposed to outcome evaluation for children either individually or collectively at service level, as evident in the following study.

Coyne et al's (2006) qualitative study (individual and focus group interviews) was focused at a micro level, investigating hospitalised (two children's hospitals and one district hospital) children's (55 children aged 7-18 years with acute (n=27) and chronic (n=28) illnesses) experiences of participation in the process of consultation and decision-making (and potential facilitating and hindering factors in this process). While the report highlighted that children had varying experiences of involvement in consultation and decision-making the strongest finding to emerge was lack of consultation with children. Similar to earlier studies in GP and outpatient settings, consultations predominantly took place between parents and health professionals, leaving children without a voice. Similar to others (Runeson et al, 2001; Hallstrom and Elander, 2005), Coyne et al (2006) highlighted many factors hindering children's active participation, most notably health professional communication styles, attitudes and behaviours, and parent interventions. Children reported being afraid to ask questions because they did not want to cause trouble, they found it difficult to contact health professionals and had limited time with health professionals. Being ignored, disbelieved and not listened to left children with a torrent of negative feelings, such as disappointment, betrayal, sadness, loneliness, confusion and anger. Children themselves wanted involvement in the consultation process. Facilitating factors were, knowing health professionals, being of an older age and having time to discuss, clarify and absorb information. Children's desire to be involved suggests that children themselves feel competent to participate, but are inhibited by the environment others provide (Kelsey and Abelson-Mitchell, 2007). In addition to health professionals, parents influenced the degree to which children were involved in the consultation process, by either supporting them in interpreting the information or constraining them by answering on their behalf, and reprimanding them for interrupting or withholding information (Coyne et al, 2006). Coyne et al (2006) stated that parents' interventions were probably protective, however postulated that this could lead children to become accustomed to their parents acting as their advocates. This could potentially

impinge on the opportunity for children to develop their own participation skills. This equates with Kieckhefer and Trahms (2000) contention that if everything is done for the child, even in early childhood, then on reaching adolescence and beyond there is a sudden transfer of responsibility without adequate parent or child preparation. In talking about the dominant controlling behaviours of adults (health professionals and parents), Kilkelly and Donnelly (2006:12) highlighted:

> "This illustrates the power imbalance that militates against the child's right to participate being vindicated in the healthcare setting, where their subordination to parental authority is compounded by a feeling of inferiority to the health professional. The legal duty to vindicate the child's right to be heard is aimed at addressing this imbalance in favour of the child's participation in the process. For parents, however, this is not without difficulty, particularly when they may believe that giving rights to their children is a zero-sum game which sees them relinquish all parental power."

In their study, Kilkelly and Donnelly (2006) investigated the extent to which children were listened to in healthcare settings within a legal framework (according to Article 12 UNCRC), from the perspective of children (n=52), parents (n=30) and a range of health professionals[27] (n=50). While Kilkelly and Donnelly (2006) reported similar practices, facilitators and barriers to children's participation in consultation[28] as Coyne et al (2006), they believed that parents and health professionals limited understanding of the rights of children was hugely influential in affecting children's participation in their healthcare. For instance, it was rare for parents to criticise health professionals for failing to directly communicate with, or inform, their child. Parents acquiesced with their child's limited involvement and were more likely to complain about their own marginalisation or exclusion from the consultation, when health professionals communicated directly with, or gave excessive information to, their child. Parents' felt they were acting in their child's

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[27] Individual interviews were undertaken with GPs (2), nurses (4), dentists (2), A&E doctor (1), ENT consultants (2), play specialist (2), psychologist (1), radiographer (1), social worker (2), anaesthetist (3) and dermatologist (2). Additionally, three group interviews were held with staff (mainly nursing) of a children's unit in a general hospital, a group of hospital interns (also in general hospital), and with tutors, lecturers and professors involved in education and training a range of health professionals.

[28] Barriers included health professionals' personality/attitudes, lack of communication skills training, lack of colleagues shared approach, limited resources (time and physical environment – space, privacy, child friendliness) and parent interventions. Factors positively evaluated were addressing the child directly, an age appropriate approach, preparing children for what was to happen, being honest, giving children an opportunity to ask questions, giving children choices, being light hearted and good humoured, and an age appropriate healthcare environment.

*best interests* by protecting them from anxiety and distress and lacked awareness of children's right to be involved. Furthermore, parents were of the opinion that health professionals should speak to them first. This would then enable them to screen what their child should be informed. Parents believed that they were in the best position, not health professionals, to determine what was in their child's best interest in terms of their level of involvement in the consultation process. However, as Savage and Callery (2007:364) contended:

> "The "best interests" principle of protecting children, however, could be counterproductive to developing partnerships if used by adults to justify excluding or limiting children's involvement in health consultations."

Similar to other studies (e.g. Buford, 2005) children in Coyne et al's (2006) study relayed their reliance on their parents because of the ineffective communication style employed by health professionals. Yet, parents often feel unsupported in their role as supportive mediator (Clarke and Fletcher, 2003). They feel unsure about their role (Tourigny, Chapados and Pineault, 2005) and what will happen (Smith and Callery, 2005), requiring ongoing education (Buford, 2005). This highlights the need to avoid the dominant assumption that parents are in the best position to prepare their child. Would improved and more effective health professional-child communication reduce children's reliance on their parents' as communication brokers? Indeed, of most importance to children was their inclusion in the communication process (listened to, heard and given an opportunity to ask questions) and not necessarily involvement in serious decision-making (Coyne et al, 2006). Perhaps, we have jumped too quickly to involving children in decision-making without beginning with the forerunner, communicating directly with children. First children may have to become accustomed to and comfortable with adults communicating with them, as historically this was not the norm.

In their small-scale study (n=10), Kelsey and Abelson-Mitchell (2007) highlighted that the main barrier to children's (12-16 years) inclusion in decision-making was lack of communication, with children themselves highlighting effective communication as an important element inherent within the decision-making process. Young people felt powerless and could not say *'no don't do that'* because of their lack of knowledge

(Kelsey, Abelson-Mitchell and Skirton, 2007). This highlights the pre-requisite for adequate, accurate and comprehensible information to enhance children's decision-making capacity as Hallstrom and Elander (2005:235) precisely outlined:

> "A prerequisite to be able to participate is to be allowed to do so and to receive information that is adapted to the child's needs and wishes, and is about the alternatives and the opportunity to reflect, to ask questions, and also to refuse to participate."

This could explain some of Coyne et al's (2008) findings. Perhaps children did not want to decide because they had insufficient information to make the required decision and consequently relied on their parents support. Coad and Houston (2006) reported similar findings in their review of hospital and community based services and highlighted that there is limited evaluative research regarding interactions between staff-children-parents, especially from children's perspective. Yet, encouraging child participation in healthcare consults and decisions is dependent upon the ability of health professionals to manage a three-way dialogical relationship between themselves, the child and parent(s), in the context of a busy ward (Dixon-Woods, Young and Heney, 1999; Coad and Houston, 2006). Pyorala's (2004) Finish study, of audio-recorded interactions of children (7-9 years) and young people's (13-15 years) participatory roles in diabetes dietary counselling, illustrated the complexity of multi-party (two, three or four and more) relationships. Children were active participants in two party encounters, whereas in three party encounters, and similar to Coyne et al's (2006) findings, children became passive bystanders with parents speaking on their behalf, complementing or correcting their talk. Thus, the more adults numbers the more marginalised the child. Hence, in the words of Hallstrom and Elander (2005:230):

> "There must be communication in order to emphasis the importance of participation of everybody involved in necessary decisions. The parent and the child have to inform staff members about the child's condition and, when staff members explain about procedures, they have to confirm that family members have understood."

In spite of this, hospitalised children themselves frequently claim that they do not receive optimal, sufficient and comprehensible information about their healthcare (see Section 2.3.5). Perhaps one explanation for this inadequate communication is the *ad hoc* and generic training for health professionals (across various disciplines) in communicating

with children (Kilkelly and Donnelly, 2006).[29] However, more empirical evidence is needed before such a claim can be confirmed as Kilkelly and Donnelly (2006) reported that detailed information about formal education relating to communication with children was not always available. Kilkelly and Donnelly (2006) did highlight that there was some evidence of communication skills training within children's nursing programmes.[30] Despite this, it is unknown how much time was allocated to; who was responsible for, what and how communication skills were actually taught (and the consistency across programmes) (see Chant et al, 2002a&b). Furthermore, how nurses perform communication skills in real-life clinical settings following training requires further investigation. As highlighted in the introduction (Section 1.0), the UK National Service Framework for Children, Young People and Maternity Services recommended that all staff working with children be adequately trained in communication skills. However, a confounding problem is the uncertainty on what constitutes best practice because in the nomenclature of Callery (2005:12), "the evidence base in communication with children in health care is woefully inadequate". Without knowledge of what child patients' value, in terms of communication, how can we effectively meet their information and communication needs?

### **2.4.2.** Hospitalised children's information and communication needs

At the outset of this thesis, there were limited published papers sourced that specifically addressed the information and communication needs of hospitalised children. A number of dated studies had examined the frequency, duration and function of nurse-child encounters in addition to the influence of parental presence on nurse child contacts (Schulman, Kasper and Child, 1970; Cleary, 1979). Outcomes of these studies suggested that nurse child-patient interactions were brief and primarily initiated for performing

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[29] Kilkelly and Donnelly (2006) reported that most health professionals reported learning through informal (experiences, observing role-models) rather than formal (academic theoretical and practical modules) methods about how to interact with children in healthcare. Suggested barriers to teaching communication skills were limited time with a packed curriculum, a lack of appreciation of the importance communication skills training and the perception that communication skills could not be taught as they are not acquired but rather innate.

[30] From an Australian perspective, Gough et al (2008 in press) report on a communication skills simulation training programme for graduate nurses in paediatrics. However, the main focus of this training was to educate nurses about how to deal with difficult communication situations with parents.

nursing functions rather than for providing children with emotional support and social stimulation. From the late 1990s onwards, some preliminary work began to emerge which was more explicit in exploring the communication and information needs of chronically ill children and young people (Hooker, 1997; Beresford and Sloper, 2003; Young et al, 2003). Since then, and particularly in the last few years, studies have started to expand to children's general medical and surgical information and communication needs (Shin and White-Traut, 2005; Smith and Callery, 2005; Martenson and Fagerskiold, 2007; Wales et al, 2008[31]). Owing to the limited number of studies and diversity across these studies, in terms of designs, methods, contexts and sampling, I discuss them individually, as opposed to synergistically, however I do debate parity and disparities among the studies.

Using a sort card instrument to explore chronically ill teenagers' information needs, Hooker (1997) identified a mismatch between teenagers' (13-17 years; n=7) actual information needs and health professionals' (n=10) assumptions of teenagers' information priorities on one regional paediatric oncology unit. Although health professionals (2 consultant oncologists, 6 nurses, 1 social worker and 1 psychologist) accurately perceived teenagers information priorities in relation to diagnosis, prognosis and treatment, they overrated teenagers need for information in relation to psychosocial issues (e.g. the impact of their illness on lifestyle, appearance, relationships and usual activities) and underestimated teenagers need for information about the future. Lack of individualised patient-centred communication could account for this mismatch between teenagers' actual information needs and health professionals' assumptions of teenagers' information priorities. With a larger (n=63) and more diverse sample, Beresford and Sloper (2003) explored chronically ill (juvenile chronic arthritis, cystic fibrosis, diabetes, epilepsy and muscular dystrophy) adolescents' (10-16 years) experiences of communicating with doctors. Adolescents identified doctors' familiarity, power status, communication skills and other party presence (e.g. medical students), in addition to their own personality and communication skills (not knowing how to ask questions), as

[31] Wales et al (2008) undertook a multi-level assessment of communication at Sydney Children's Hospital, however did not present children's experiences in their published paper.

influential factors inhibiting effective communication.[32] Different to Hooker's (1997) findings, young people in this study (Beresford and Sloper, 2003) considered receiving psychosocial information (e.g. how to manage school, dealing with peers, coping with negative emotions and maintaining a positive outlook on life) to be as important as knowing about their condition and its management. Interestingly though, young people rarely mentioned health professionals to be a resource in terms of providing these psychosocial communication needs, but rather their friends and family. This might explain the difference in Hooker's (1997) findings; perhaps young people did not see the provision of psychosocial information as part of the health professional role, but rather their family and friends. However, the lack of focus on psychosocial information left young people with a sense that health professionals lacked interest in, or awareness of, the wider implications of being an adolescent with a chronic illness (Beresford and Sloper, 2003). This meant the communication process gave precedence to the doctor's physical agenda and not the individual psychosocial needs of young people themselves.

Young people viewed the presence of their parents as either inhibitive or supportive (Beresford and Sloper, 2003). This supports Young et al's (2003) investigation of chronically ill young people's (8-17 years; n=13), and their parents, accounts of communication about cancer in childhood in one paediatric oncology unit in England. While young people welcomed parent involvement, they also expressed unease with constraining aspects of the parent role. Parents themselves recognised their executive style of setting information boundaries and censoring, filtering or delaying information before it reached young people. Parents did this to enable them to deal with their own initial grief, to manage their own optimistic identity as parents and protect their young child's wellbeing. Young people did not overtly regard their parent's involvement as inappropriate, with young people expressing mixed views about the form of disclosure (mainly diagnosis). Some thought it was appropriate for their parents to receive the

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[32] Adolescents of a younger age ascribed doctors a high status. Doctors often communicated directly with parents, asked many questions (resulting in one-way conversations) and employed over technical language. The presence of medical students impinged upon young people's privacy and reduced their disclosure. Young people felt their own inability and reluctance to ask questions further inhibited the communication process.

information before they did. Others felt it was better to receive the information at the same time as their parents. Whereas, yet others reported no strong preference either way. Young et al (2003) reported that almost all of the young people had, at different times, embraced, even actively cultivated, their parents as communication buffers, to limit their exposure to overwhelming information and shield them from the burden of answering questions. Age was not an influential factor in explaining the different needs and preferences of young people, with some younger children requesting detailed information and some older children wanting only basic details. Similar to Coyne et al's (2006) study, children depended on their parents because they did not see themselves as having direct access to information from doctors, rather occupying a marginal position in consultations and therefore thought their priorities were of little interest.

Acutely ill children also highlighted the need for health professionals to show empathy and understanding to the emotional impact of their illness (road traffic accident (RTA)) and not just to treat their physical trauma needs (head injuries and bone fractures) (Salter and Stallard, 2004). Salter and Stallard (2004) undertook a secondary analysis of data to report on children and young people's (7-18 years; n=158) views of their contact with emergency medical services following a RTA. While some child participants relayed positive statements, 40% reported negative comments about their experiences. In relation to communication, children felt they had not received adequate information about what was going to happen and what might be wrong with them. Consequently, they often drew their own interpretations especially in relation to physical restriction, which although a common procedure for RTA victims, scared young people and led them to think that something was wrong. While one might expect such fears, because of the unforeseen and sudden nature of the accident, children awaiting elective surgery expressed similar concerns and worries about their impending hospitalisation (Smith and Callery, 2005).

Using informal interviews and the draw and write technique, Smith and Callery (2005) explored children's (aged 7-11 years; n=9) information needs prior to a planned hospital admission for surgery. Of particular concern was that children knew very little about hospital, their forthcoming admission or their surgery. Children identified a plethora of

questions, sixty-one in total, about things they wanted to know about their impending hospital admission. None of the children had received information directly from the hospital or health professionals. Similar to Bray (2007a), the information children did possess, they had sourced from a variety of mediums such as television, friends, relatives and leaflets distributed to parents (written for adult audiences and containing generic information). As previously mentioned, parents were not best placed to prepare their child because they were often unsure themselves about their child's operation and of what the children's hospital would be like. As Smith and Callery (2005) collected information from children prior to their hospital admission, it is unknown whether these children received any information while in hospital.

Limited research effort has focused specifically on communication in paediatric in-patient settings and for children admitted for wide-ranging medical and surgical care. One study sourced was Shin and White-Traut's (2005) observational study, which involved young children (aged 5-6 years; n=8) with acute illnesses (e.g. gastroenteritis and pneumonia). Shin and White-Traut (2005) videotaped nurse-child-mother interactions for four hours (14.00-18.00 hours) a day, for two days, on a 60 bedded inpatient paediatric unit (tertiary care medical centre) in Korea. The purpose was to describe patterns and characteristics of nurse-child and nurse-parent interactions. The majority of interactions were nurse initiated, to perform nursing activities and lasted on average four minutes. This is similar to earlier findings reported by Schulman, Kasper and Child (1970) and Cleary (1979). However, Shin and White-Traut (2005) did identify nurses' attempting to engage children in dialogue, by asking their opinions or seeking information (53% of interactions occurred between the nurse and child and 33% between the nurse and parent). Yet, children did not actively respond, culminating in their passive participation. Observer reactivity (researcher in corner of room and limited timeframe for observations) could have had an impact on the study outcomes. Other influential factors could have been the inpatient setting, cultural practice and/or child's age, because in Sweden, Baggens (2001) and more recently Martenson and Fagerskiold (2007) reported different findings with both younger and older children, respectively. In both these studies,

children attempted to hold a more active role, at visits to health centres and outpatient settings.

Baggens (2001) audio-taped 44 family visits to child health centres (n=46 parents, 44 children, 10 siblings and 8 nurses) and reported that for children, aged 3 years to 5.5 years, parental referral to situational matters[33] was an important ticket for children to gain entry into, and participate, in the conversation. Although children as a whole introduced few topics into the conversation, when they did, it resulted in other adult participants accepting these topics, albeit briefly, before a new topic was re-introduced by an adult participant. Martenson and Fagerskiold (2007) carried out an observational study (field notes from 76 observations of information exchange and excerpts from medical records) at three separate paediatric outpatient settings in a university hospital: a day care unit, neuro-urology and bowel disorder unit and diabetic clinic. The aim was to describe the information exchange between children (10-17 years; n=28), their parents and health professionals (paediatric nurses, enrolled nurses and paediatricians) during nursing care. Observations were not restricted to consulting rooms but also extended to corridors and waiting areas. The core theme was balancing the circumstances in the information exchange to varying degrees, based on six inter-related categories, *taking part, trust, being in touch, mutuality, getting facts* and *family influence.* For instance, *getting facts* was stabilising when information was shared, but counterproductive or constraining when staff controlled it as a one-way process of communication. Similarly, *family influence* was either restraining when the family spoke in its own interests or stabilising when the child perceived it to be caring and confirmative. However, children appeared to try to enhance their own situation by finding out as much as they were able to, sharing their own knowledge with the staff and participating in social interactions with them. Thus, while children were reliant on adults, they also tried to manage what was going to happen to them by playing an active or passive role. They tried to balance what was stabilising or supportive with what was counteractive or restraining. This back and forth family

[33] Baggens (2001) referred to situational matters as times where parents made reference to what the child did in the ongoing situation at the child health centre, the physical or social environment or other aspects related to just that moment.

movement between encouraging and controlling can be supportive but it can also be confusing (Martenson and Fagerskiold, 2007). These studies while offering valuable insights, neglected to explore the views of children themselves.

## 2.5. Conclusion

This chapter presented an overview of a range of literature to contextualise the rationale for selecting the focus of the thesis, namely the communication process between hospitalised children and the healthcare professionals caring for them. It began with an outline of the historical influences, which shaped the development of care for children in hospital. Pursuing this there was a brief mention of some of the debated effects, both positive and negative, of childhood hospitalisation. This led to the identification of the main drivers for change, which worked to ensure that the welfare of hospitalised children received the attention it deserved. While many recommendations have been put forward, over many years, for the care of children in hospital, such as, age appropriate environments, adequate play and education facilities, appropriately trained staff, age appropriate information and involvement of children in consultations and decisions that affect them; parental presence, participation and FCC have been chiefly topical, receiving the most research attention.

Despite the lack of hard, and soft, evidence of its effectiveness, there is a passive acceptance of FCC as the central tenet and fundamental principle of providing quality care to hospitalised children. There has been a plethora of international studies which have explored parental roles, involvement, participation, needs, experiences, interactions and relationships, from the perspectives of both parents themselves and health professionals. What is missing within this perfusion of literature is the voice of the child. How can we effectively shape services for sick children and claim to be responsive to their user needs without eliciting their views? This is essential because as illustrated previously FCC encompasses far more than merely parent presence, involvement and participation. It is a holistic family perspective, which embraces respect for child and family, recognition of family diversity and individuality and involves collaboration, negotiation, communication with, and empowerment of, child and family. Both children

and parents engage as active partners with health professionals in care, treatment and decision-making.

A number of studies focused on children's participation in consultation and decision-making. These revealed the marginalisation of children by adult (parent and health professionals) domination and identified the existence of conflicting tensions between parents and health professionals regarding children's involvement in the consultation process. However, (with a few recent exceptions which emerged since the instigation of this study) they failed to explore children's views and interactions in inpatient hospital settings. Arguably, while the emergence of the UNCRC in the late 1980s resulted in monumental changes in thinking and practices about involving children in all matters that affect them, within the context of healthcare children's agency remains largely inhibited and relatively under-researched (Sartain, Clarke and Heyman, 2000). The muted voice of children reflects adult dominant power and permits an ongoing inequitable relationship. This is not to devalue the voice, role and positioning of parents in the care of their sick hospitalised child. Instead, it is to ensure that children remain visible at the heart of paediatric nursing practice, with children's invisibility evident by the negligible volume of studies addressing the child patient-health professional communication process.

With the recent drive towards consumerism, a number of studies have directly explored children's views of hospital and healthcare. One dominant concern to emerge from these studies, for hospitalised children, of all ages, was lack of communication. There is much anecdotal posturing about the importance and complexity of effectively communicating with sick hospitalised children (e.g. Jolly, 1981; Parish, 1986; May, 1999). While the necessity for skills modification to integrate cognitive and psychosocial developmental approaches into communication with children at different ages is advocated (Thompson, 1991; Chesterfield, 1992; May, 1999), there is little in the way of supportive empirical evidence. It is timely to undertake child-focused studies to substantiate these assumptions and identify specific behaviours children value in terms of child appropriate communication, to build a body of evidence addressing communication between children and health professionals.

Since the conception of this thesis, a number of studies specifically exploring hospitalised children's information and communication needs have emerged. The diversity of these studies makes it difficult to synergise and transfer findings to other contexts especially because they predominantly focus on the needs of chronically ill children in outpatient or clinic settings. Limited knowledge exists on the impromptu nature of communication for children in hospital with general medical and surgical conditions. Thus, the aim of this thesis was to address this gap and contribute to this limited body of knowledge by providing insight into children's, of various ages and with diverse medical and surgical conditions, perspectives of communicating with health professionals in an in-patient hospital setting. Prior to presenting the methodology employed, the next chapter will provide an overview of background communication theory and present two theoretical frameworks adopted to guide this study.

# CHAPTER 3: THEORETICAL FRAMEWORK

## 3.0. Introduction

There are many different viewpoints on the appropriateness of employing a theoretical framework at the outset of an inquiry (Sandelowski, 1993). Some caution against it, arguing that it might impose preconceived ideas on emergent data (Hammersley and Atkinson, 2007). Others believe it is crucial that all studies, including ethnography, make use of an underlying theory or model (Fettrrman, 1998; Wolcott, 1999). I grappled with this conflict of whether or not to begin with a theoretical framework to guide the study and furthermore with identifying what this theoretical framework should be. After much back and forth altercations I moved beyond this dichotomy of either beginning with (frame to guide the study) or ending with (emerged/generated from data) a theoretical framework. The use of a theoretical framework adds depth and rigour to the research study by illuminating areas not clearly visible and by providing a systematic structure to the research and analysis of findings (Taylor, 2004). One plausible criticism of previous studies, exploring health professionals' communication practices with children, is that they neglect to recognise the role theory may play in interpreting and explaining their findings (Dixon-Woods, Young and Heney, 2005). It is vital that nurses are able to conceptualise what they are doing, for theory guides practice. Thus, I decided that one begins with some theory, generated from pre-existing literature, to guide the research like a map. This theory is subject to ongoing modification throughout the research through comparison with data collected and analysed. This section presents existing communication theories and details the two theoretical frameworks, which guided the research. Prior to this it is my contention that it is necessary to advance a definition of communication.

## 3.1. Communication: Searching for a Definition

Although regarded as an ostensibly simple concept, communication if investigated further is a complex, nuanced, multifaceted phenomenon, "that is at one and the same time ubiquitous yet elusive, prosaic yet mysterious, straightforward yet frustratingly prone to

failure" (Hargie and Dickson, 2004:12). With interpersonal skills forming the "epicentre of our social existence" (Hargie and Dickson, 2004:3), we simply cannot avoid communicating; it is incessant and inevitable (Ellis, 1995; McCabe and Timmins, 2006; Crawford, Brown and Bonham, 2006). The literature illustrates the diverse intricate nature of the field of communication by lack of consensus on a uniform definition. Traced to its Latin roots, *'to communicate'* translates as *"to share"* and *"to make common"* (Hargie and Dickson, 2004:12). Hargie and Dickson (2004:41) contend that the complexity of communication defies definition. Instead, a number of its [communication] key attributes can be easily recognied; "interpersonal communication can be thought of as a process that is transactional, purposeful, multi-dimensional, irreversible and (possibly) inevitable". For many, the term is equivalent to a social process of interaction between people, or a reciprocal process of information exchange (Iveson-Iveson, 1983; Groenman, Slevin and Buckenham, 1992).

> "Interpersonal communication takes place when people – adults and children – interact. They talk, listen, observe and react to each other, exchanging all kinds of information, in many different ways.....A useful way of thinking about interpersonal communication is as a series of messages – information – which you send out to other people and messages which you received from them, through seeing, hearing or touching one another" (Petrie, 1997:6).

Arnold (1999a) describes communication as a process through which human-to-human relationships[34] are established and common goals achieved. Similarly, McCabe and Timmins (2006:11/12) propose the following definition:

> "Communication is probably best described as a complex, unconscious or deliberate process that influences the development of interpersonal or professional relationships and outcomes of interactions, regardless of the context".

Others would perhaps refute the phrase *'regardless of context'*, because all communication takes place in a context, which exerts crucial pressure on the communication process, as the following quotation illustrates:

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[34] The terms interpersonal, therapeutic and professional relationships are often referred to in the context of communication. To distinguish between these terms the following explanations are offered. Interpersonal relationship refers to the relationship which takes place when people interact (talk, listen, exchange information etc.) with each other. This differs to a therapeutic relationship which has a more defined health related purpose to enhance patient wellbeing both physically and psychologically by promoting recovery and supporting self-care functioning. Professional relationship refers to the relationship that takes place between the nurse and patient in the context of health care as opposed to on a personal social level.

> "All communication is context bound. We can think of spatial, temporal, relational and sometimes organisational frameworks within which it [communication] is embedded. The personal characteristics of the participants together with features of the shared situation act to shape the interaction that transpires and both may be influenced, to some extent, in consequence" (Hargie and Dickson, 2004:41).

Yet, McCabe and Timmins (2006:9) acknowledge that "it could be said that communication is not a simple process in any interaction or situation and to regard it as such would require that the dynamic individual and contextual nature of communication be ignored or underestimated". Before deciding on an operational definition of what communication entails for the purpose of this thesis, it is necessary to examine how the dynamic individual and context are represented within existing communication models.

### 3.2. Selecting a Guiding Theoretical Framework

In an attempt to source an appropriate communication framework[35] to guide this thesis a number of communication models[36] were sourced and their applicability explored. Appendix 3 gives an overview of a number of these models, their origin, what informed their development and their key elements. These models traversed, doctor-patient interactions/relationships in adult settings (Szasz and Hollender, 1956; Mead and Bower, 2000), health professional-family member relationships in adult and child settings (Thorne and Robinson, 1988), nurse interactions/relationships in adult settings (Morse et al, 1992 [2006]; Fosbinder, 1994; Morse, Havens and Wilson, 1997), nurse-parent/family interactions in paediatric settings (Casey, 1995; Alsop-Shields, 2002; Figueroa-Altman et al, 2005), adult-centred models adapted for use in paediatric settings and incorporated into the philosophy of FCC (Curley, 1988; Ahmann, 1994); health professional-child interactions (Syndor-Greenberg and Dokken, 2001) and partnership/negotiated care models for use in paediatric settings (Casey and Mobbs, 1988; Casey, 1988; Smith, 1995).[37] The prevailing emphasis within these models was communication with the adult

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[35] I use the word framework in the context of the theoretical framework(s) guiding the study.

[36] When I use the term model I am referring to previous models developed in relation to communication (although different terms are often used interchangeably within the literature).

[37] Various means were used to develop these models; reviewing theoretical/conceptual/empirical and autobiographical literature (Szasz and Hollender, 1956; Casey and Mobbs, 1988; Morse et al, 1992; Morse, Havens and Wilson, 1997; Mead and Bower, 2000), reflection on practice (Smith, 1995), exploring family member's (Thorne and Robinson, 1988), adult patient's (Fosbinder, 1995), parents (Alsop-Shields, 2002;

patient or parent. For the purpose of this thesis, I concentrate on those models (and their origins) suggested for use with parents and their children.

Within the context of family-centred care (FCC), Ahmann (1994:115) proposed, "there are several communication models that can be useful as nurses learn to restructure communication with parents so that it becomes more collaborative". Two models of communication suggested by Ahmann (1994) and adapted for use within the context of FCC were the LEARN model and the Nursing Mutual Participation Model of Care (NMPMC). It was evident that the focus for usage of these communication models within FCC was primarily about building collaborative relationships with parents. The LEARN model was first proposed by Berlin and Fowkes (1983) as a teaching framework to increase awareness and cultural sensitivity among health professionals. Berlin and Fowkes (1983:934) stated that they developed this model by "building on methods of elicitation suggested in the literature". The first acronym *L,* representing *Listen*, does place emphasis on listening to and understanding patient's preferences, for instance Berlin and Fowkes (1983:935) suggest asking the patient "what do you feel may be causing your problem?" and E; representing *Explain*, in which appropriate information about the care strategy is conveyed to the patient. The letter A, signifing *Acknowledge,* highlights the need to acknowledge the patient's explanatory model and discuss similarities and differences to that of the health professional's explanatory model. *Recommend* and *Negotiate* treatment denotes R and N respectively, which involves recommending through negotiation a plan of treatment which takes cognisance of both patient and health professional explanatory models. In recommending the use of the LEARN mnemonic within the context of FCC, Ahmann (1994:115) changed *patient* to *family* to elicit family's perception of the problem. It was clear from Ahmann's (1994) writing that when she referred to the family she meant parent(s), with attention predominantly given to the collaborative parent-health professional relationship.

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Figueroa-Altman et al, 2005), health professionals (Casey, 1995; Alsop-Shields, 2002; Figueroa-Altman et al, 2005) and children's (Syndor-Greenberg and Dokken, 2001) perspectives.

The second communication model proposed by Ahmann (1994) was Mutual Participation. The Mutual Participation model emerged for employment within medical interactions in adult settings (Szasz and Hollender, 1956; Brody, 1980). However, its use evolved into nursing and pediatric care (Curley, 1988; Ahmann, 1994). For instance, Curley (1988) used a quasi-experimental design to study the effects of the mutual participation model of care on perceived environmental stress of 33 parents of children aged 28 months in a pediatric intensive care unit (PICU). Curley (1988:684) hypothesized that the "NMPMC provides the framework for nursing interactions that foster active parental involvement with their critically ill child" and concluded that the NMPMC was helpful in alleviating parental stress; particularly stress directly related to the interruption of the parent-child relationship in the PICU setting. While acknowledging that children within Curley's study were toddlers, the overriding focus was on the parent. Similarly, as highlighted above when proposing the incorporation of the NMPMC within the context of FCC Ahmann's (1994) focus was essentially on the parent. Perhaps this was not surprising considering that the origin of this aforementioned NMPMC was the adult patient.

As mentioned above, the Mutual Participation model stemmed from Szasz and Hollender's attempt to refine Parson's concept of the passivity of the role of the sick patient, and analyse its applicability to chronic illness. Szasz and Hollender (1956) proposed three paradigms of the doctor *adult* patient relationship. These were *activity-passivity*; *guidance-cooperation* and *mutual participation*. Szasz and Hollender highlighted that the applicability of these three different types of therapeutic relationships were dependent upon individual circumstances, mainly illness acuity. For instance, *activity-passivity* was suited for emergencies, *guidance-cooperation* was relevant in cases that were more acute and finally *mutual participation* was applicable for patients with chronic illnesses. Szasz and Hollender (1956) introduced this paradigm, *mutual participation*, for use with chronically ill adults. The *mutual participation* model is based on the premise that the health professional is not the only expert and might not always know what is best for the patient (Ahmann, 1994); recognising that those with chronic illnesses are experts to. This neglects to address the needs of those with acute illnesses.

Somewhat similar to Szasz and Hollender (1956) three paradigms of the doctor adult patient relationship, in terms of equity of patient health professional involvement and authority, Casey (1995) devised a model entitled "involvement in care: nursing approaches" to describe the practical implications of the effect that communication and nursing style had on parent involvement in their child's care (see Appendix 3). However, data were collected, about children in hospital, their families, what care they required and the families involvement in that care, through structured interviews with nursing staff and from secondary sources such as medical and nursing records.[38]

Although not specifically communication models but rather a philosophical model for nursing care, paediatric models of care emerged in the mid to late 1980s to reflect such concepts as partnership and negotiated care (Casey, 1988; Smith, 1995). In her proposed model, Casey (1988) strongly recommended that the process of nursing be carried out in *partnership* with the child patient and his/her family; a process of negotiation is entered. While Casey's (1988) model created a surge of interest, no information was provided on what informed the model development, or on how to operate this partnership in practice. Mason (1995) argued that Casey's model lacked structure, although Casey justifies this by stating that the model aims for adaptability to various paediatric specialties. In presenting the Nottingham model, developed in conjunction with Nottingham children's nurses, Smith (1995) similarly advocated for an equal partnership between health professionals and child patients, parents and family. Smith (1995:23) highlighted that to "enable a young child to participate as fully as possible within the activities involved in the caring process, the nurse must possess excellent communication and interpersonal skills". The Nottingham model was constructed around two main concepts, one of child and family focused care and two of negotiated care. Smith (1995) recognised the child as a unique individual, who is a member of a complex unit, the family, and agreed with Casey (1988) that the best person to care for the child was his/her family; with specifically trained health professionals providing additional assistance. Smith's model

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[38] Another model, a nurse-adult patient emotional engagement model, proposed by Morse et al (1992; 2006) (developed from autobiographical and biographical accounts of caregiver patient interactions from lay literature) has some similarities with Casey's model (see Appendix 3).

offers valuable guidance for nursing practice, however, is limited because it was developed based on the philosophy and practice in one children's unit. In a qualitative study across four countries, Shields and King (2001a&b) explored parents and staffs (doctors, nurses and allied health professionals) attitudes about the care of hospitalised children. Communication emerged as the dominant theme across all four countries for both staff and parents. Following this study, Alsop-Shields (2002) proposed a *Parent-Staff Model of Pediatric Care.* Alsop-Shields (2002:446) stated that the model was "a way of looking at the family and interacting with them rather than a way of delivering any specific type of care". The parent and child are one single unified entity. They are in hospital (environment) surrounded by hospital staff - a separate entity. Communication is the linking factor between these two entities. Health (or depletion of it) is inherent within the model. However, within this model the action is the "communication between parents and staff" (Alsop-Shields, 2002:446). Can these aforementioned models claim to specifically reflect nursing care within children's hospital settings without including the voice of the child patient?

In an attempt to improve partnerships with children and families, Figueroa-Altman et al (2005) devised the mnemonic KIDSCARE (knock, introduce, determine, safety, clean hands, advocate, respond and explain) to represent actions nurses could instigate to promote relationships with children and their families. However, like other models this mnemonic did not symbolise children's voices with ideas for KIDSCARE stemming from discussions between a bedside nurse, a Clinical Nurse Specialist (Mental Health) and a mother of a chronically ill child. One model sourced, which developed following conversations with *'several'* children and adolescents (aged 4 to 17 years) about communicating with healthcare professionals, was Sydnor-Greenberg and Dokken's (2001) CLEAR model. CLEAR represents *context*, *listening*, *empowerment*, *advice* and *reassurance.* Children highlighted that they wanted health professionals to see them in *context.* This meant that they wanted healthcare professionals to regard them as a whole person by asking them personal questions about their life (e.g., school, friends, activities) outside the chronic or acute illness they were experiencing. Children valued when health professionals *listened to* them and when they were included. They felt *empowered* when

health professionals communicated with them directly, as opposed to talking to their parents about them in their presence. Here, the concept of empowerment related to receiving information and being prepared about what was going to happen, what health professionals were going to do and what children themselves would be able to do. Health promotion *advice* and *being reassured* about their health were also important to children and young people. However, Syndor-Greenberg and Dokken's (2001) model is limited because they failed to specify how many children they conversed with, and they provided limited information about data collection and analysis. Indeed, they stated that they first presented the acronym CLEAR as a model for outlining what parents would like in their interactions with health professionals. Acknowledging that their discussion is "only the tip of the iceberg", Sydnor-Greenberg and Dokken (2001:226) called for "much more research, reflection, writing and training" surrounding communication between healthcare professionals and children.[39] This thesis contributes to moving this agenda forward by exploring and offering valuable insights into the nature of communication on a children's ward, from children's perspectives (chapter 6) and debating these findings within a number of different theoretical perspectives (chapter 7).

In summary, apart from the limited work of Syndor-Greenberg and Dokken (2001) the focus of existing communication models has been essentially on the adult, whether patient, family member, parent or health professional. Although there might be some similarities between the adult and child patient, one must be cautious in making this assumption. Children may differ in their conceptualisation of terms and different contexts may influence the applicability of the various elements identified. Therefore, to guide this study, I selected a neutral (by neutral I mean that this model was not aligned specifically to a population (e.g. adults) or a specific setting (e.g. outpatients)) model, the trans-

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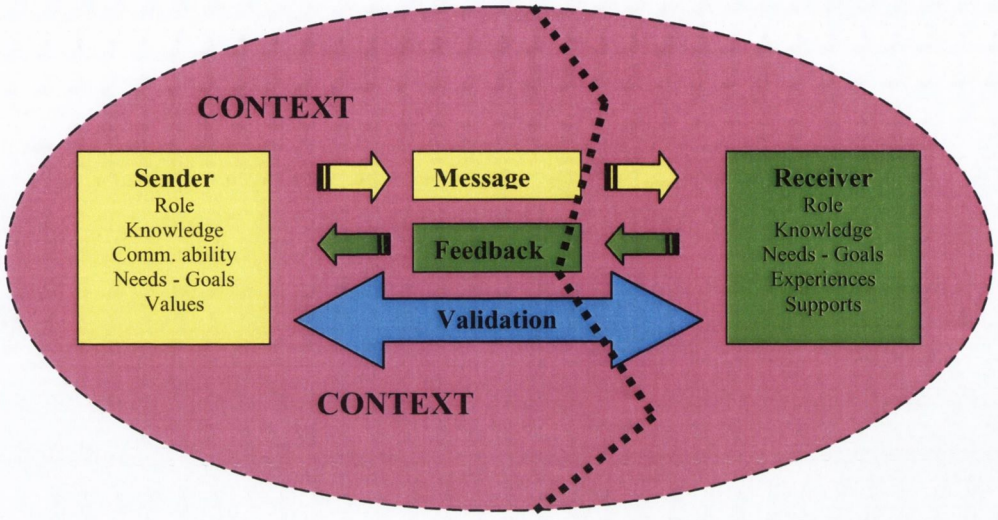
[39] Sydnor-Greenberg and Dokken (2001) offered some starting point suggestions in answer to the question: what can healthcare professionals do to encourage CLEAR communication with children? Proposed suggestions were, be aware of your own communication with children; look to other professional resources for guidance about communication with children (e.g. child development and parenting resources) and communication in general (e.g. management literature); look for new resources on healthcare communication in journals; encourage research and encourage incorporation of communication into curricula for healthcare professionals.

circular model of communication, which outlines the basic tenets of the communication process.

### 3.2.1. Circular transactional model of communication

As previously mentioned (Section 3.1), the majority of definitions describe communication as a *process*. Conventionally, communication *process* models consisted of three basic elements, sender, message and receiver (Arnold, 2007 [2003; 1999b]). This simplistic linear theory illustrated a narrow view of a one-way process of communication, which failed to take account of intrinsic (personal/professional aspects of a person, such as values, beliefs, roles, knowledge and goals) and extrinsic (immediate physical environment) complexities that resided within the communication process (McCabe and Timmins, 2006). A modernised broader view, the circular transactional process, replaced conventional unidirectional linear models with the recognition that communication was far more than a one way process that consisted of three basic elements; sender-message-receiver. While the circular transactional communciation model constitutes components similar to the linear model, it also takes cognisance of the cyclical reciprocity that takes place between communicators (sender and receiver), such as, feedback, understanding, and validation; in addition to internal and external noise and the wider context within which the communication process takes place (Arnold, 2007 [2003; 1999b]; McCabe and Timmins, 2006). Therefore, it recognises that communication does not occur in a vacuum, acknowledging that a variety of intrinsic and extrinsic factors can affect the interaction process and distort the transmission of the message; recognising that many potential barriers exist to effective communication. I selected this trans-circular model of communication (diagrammatically represented in Figure 1) to guide my reflections on the process of communication taking place between children, their parents and health professionals in the research field. This model was chosen because of its impartiality and non-aligned status (to adult population or a specific setting).

**Figure 1: Circular Transactional Model of Communication**[40]




However, although I considered this the most suitable communication model available, I recognised it had limitations, namely in relation to its conceptualisation of context. While the circular transactional model recognises the importance of contextual influences, the factors it addresses are narrow and uncritical in focus. Through its narrow and uncritical mind-set it is argued that this model over simplifies the complexity of the phenomenon of communication with children. For instance, while the need to integrate cognitive developmentally appropriate approaches into the communication process with different aged children is broadly advocated for (Thompson, 1991; Sydnor-Greenberg and Dokken, 2001), any debates outside developmental psychology, for example, children's rights, power relations and how we view and position children within society are neglected. In agreement with Rushforth (2006:146), "perhaps the most important guiding principle in selecting an appropriate theory to underpin practice is to consider the congruence of the theories offered [developmental theories] with other contemporary

[40] This model has been adopted for use and display within this thesis with permission from Elsevier Limited. This model was published in Interpersonal Relationships: Professional Communication Skills for Nurses. Arnold, E and Underman Boggs, K. (eds) Chapter 1: Arnold, E. Theoretcial Perspectives and Contemporary Issues. Page 17. Fifth Edition. Copyright: Saunders: Elsevier (2007).

notions of childhood, children's rights and child health care delivery".[41] Crawford, Brown and Bonham (2006:19) support such contentions stating that "all communication takes place in particular contexts or environments and is informed and influenced by wider political and economic structures."

For this reason, I also adopted the multi-system principles of Bronfenbrenner's (1979) ecological model of human development because such multi-systems allow for not only mutual consideration of individual child characteristics and the immediate interpersonal communication process at a micro level, but also take cognisance of wider societal environmental factors. The belief was that Bronfenbrenner's *nested systems* would offer a valuable framework to assist in moving our thinking about communication with children in hospital away from a narrow individualised focus, illuminating communication as a product of a complex set of interacting factors at individual, family, organisational and societal levels.

### **3.2.2**. Principles of ecological model of human development

Bronfenbrenner's (1979) ecological model of human development[42] acknowledges the crucial importance of studying the environment in which we behave. Within the context of this thesis, the proposition was that Bronfenbrenner's *multi-system principles* would offer a valuable framework to study communication by avoiding sole consideration of the behaviour, skills and/or qualities of healthcare professionals in isolation of structures within and between immediate and larger environments. Merely focusing on the micro interaction process would assume that communication takes place in a social vacuum. While the environment might not determine the communication process, it may constrain or facilitate it.

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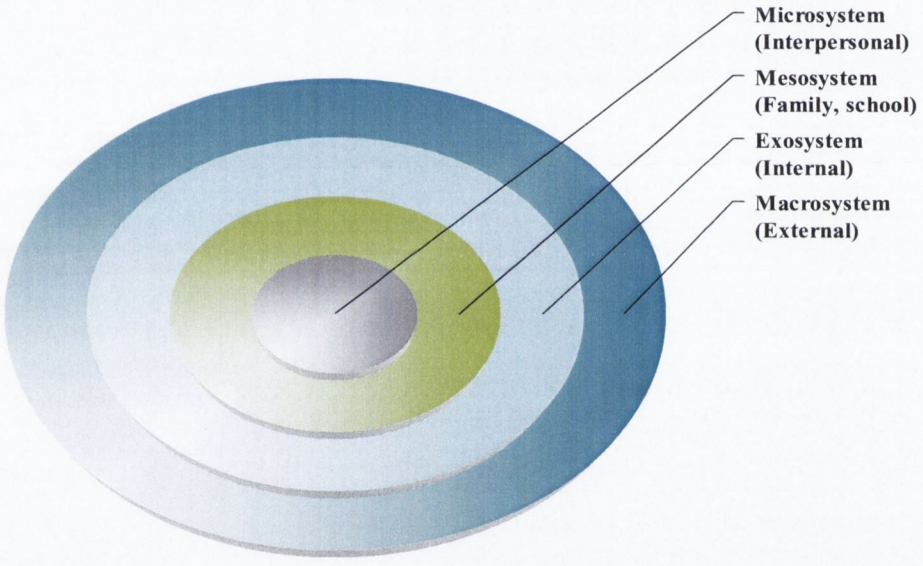
[41] In a similar vein, Garland and Kenny (2006) acknowledged the need for nurse educators to combine FCC concepts and children's rights when teaching pain management.

[42] Bronfenbrenner (1979) developed this ecological model as a way of studying children's development, believing it was necessary to look not merely at the child and his/her immediate environment, but also at the interaction of his/her larger environment.

*Multi-system principles*

Bronfenbrenner (1979) described four interrelated cyclical nested systems (micro-, meso, exo- and macrosystem) each situated inside the next, similar to a set of Russian dolls (diagrammatically illustrated in Figure 2). These systems allow for mutual consideration of the immediate interpersonal communication process at a micro level, but also take cognisance of broader macro historical, societal and cultural issues.

**Figure 2: Principles of the Ecological Model of Human Development**




*Micro-system*

The immediate environment in which the child resides at a given point in his/her life encompasses the *micro-system*[43] (Lerner, 2005). In relation to this study, the child undergoes an ecological transition, which "occurs when a person's position in the ecological environment is altered as the result of a change in role, setting, or both"

[43] Bronfenbrenner (1979:22) defined the microsystem as, "a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics".

(Bronfenbrenner, 1979:26). At the time of hospitalisation, a temporary alteration in the child's setting from home to hospital and his/her role as daughter/son, pupil to patient has occurred.[44] It is at this level that the health professional enters the framework to interact with the child. Within the context of this study, the micro-system refers to the interpersonal process of communication taking place between children and health professionals in the immediate environment (interpersonal process) of the children's ward (see Figure 2). While the micro-system is the engine, the energy that drives this model comes from much deeper sources, those situated within the other three outer systems (meso-, exo-, and macro-).

*Meso-system*

The *meso-system*[45] connects structures within the child's micro-system (e.g. home and school). Within the context of this study, this encapsulates the interrelationship between the hospital and the child's home, represented by the concept *family-centred care* (see Figure 2). Although the child has transitioned from his/her family home to the hospital, the child remains part of the family. This is expanding towards a more holistic picture emphasising the role of a wide sphere of individuals in relation to communication practices with children. The interrelations between the hospital/health professionals and home/family comprise the meso-system.

*Exo-system*

The *exo-system*[46] considers events that are perhaps happening outside the sphere of the developing person, yet still have an impact upon this person. The child does not function directly in this system. Structures within this system might affect the child by interacting with structures in the child's micro-system. In relation to communication in hospital, this

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[44] Bronfenbrenner (1979:27) gives many examples of ecological transitions one of which is "to turn to even more universal themes: becoming sick, going to hospital, getting well again".

[45] "A mesosystem comprises the interrelation among two or more settings in which the developing person actively participates (such as, for a child, the relations among home, school, and neighbourhood peer group; for an adult, among family, work, and social life)" (Bronfenbrenner, 1979:25).

[46] Bronfenbrenner (1979:25) defines an exosystem as "one or more settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing person".

might include organisational factors (e.g. work philosophy, hospital policies, staffing levels, and staff education), which do not directly involve the child, yet might influence the communication process with the child. Within the context of this study, the exo-system refers to the internal healthcare environment (see Figure 2).

*Macro-system*

The *macro-system*[47] incorporates cultural attitudes and ideologies and for the context of this study, sociological perspectives in relation to the positioning of children in society (i.e. external environment factors) (see Figure 2). Arguably, this larger macro-system has a cascading effect, which ripples through each of the other inner cyclical systems. The systems are interdependent with changes happening in one system reverberating changes in other systems. The macro-system is not static it changes through evolving historical, economic and technological advances.

*Chrono-system*

The dimension of time, which has multiple dimensions of temporality,[48] is entitled the *chrono-system* (Lerner, 2005). Bronfenbrenner captured the concept of time when he revised his theoretical propositions proposing a bio-ecological model, composed of the formulation, *process-person-context-time* (Bronfenbrenner, 1995; Bronfenbrenner and Morris, 2006). Bronfrenbrenner (1995:6/7) contended;

> "The form, power, content, and direction of the proximal processes producing development vary systematically as a joint function of the characteristics of the *developing person* (including *genetic inheritance*); of the *environment*-both immediate and more remote-in which the processes are taking place; of the nature of the *developmental outcomes* under consideration; and of the continuities and changes occurring in the environment over *time*, through the life course, and during the historical period in which the person has lived."

Within this revised model, Bronfenbrenner (1995) attributed greater recognition to the incorporation of the developing *person* within the nested contextual systems, in addition

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[47] Bronfenbrenner (1979:26) refers to a macrosystem as "consistencies in the form and content of lower-order systems (micro-, meso-, and exo-) that exist, or could exist, at the level of the subculture or the culture as a whole, along with any belief systems or ideology underlying such inconsistencies".

[48] The dimension of time incorporates both spatial context, that is the particular setting, but also the temporal context, that is the historical setting.

to recognising the influence of *time*. Within the context of this study, time refers to changing perspectives and practices over time, in relation to the developing child and their active positioning within society. Based on the preceding review of relevant communication models and drawing on the two aforementioned guiding theoretical frameworks, an operational definition of communication is now set forth.

### 3.3. Operational Definition of Communication

For the purposes of this thesis, communication is operationally defined as:

*Communication is an automatic, meditated, mutually engaging process between two or more people, within which the exchange of a message - feelings, information, opinions, ideas and knowledge – takes place. It is a multi-faceted contextual process, integrating a complex composite of skills*[49] *and an intricate set of qualities,*[50] *stimulated and modified over time by internal and external environmental factors.*[51]

The findings of this thesis will subsequently appraise the authenticity of this definition.

### 3.4. Conclusion

This chapter presented an overview of existing communication model and the two theoretical frameworks, the *circular transactional model of communication* and the multi-system principles of the *ecological model of human development,* which guided this study. The following chapter provides a comprehensive overview of the philosophical and methodological assumptions underpinning this ethnographic inquiry. In addition, it details the instigation of this approach on one children's ward in an attempt to uncover the nature of communication between children and health professionals. However, firstly the next chapter contextualises the historic positioning of children within research, which is comparative to children's social positioning within society. This provides some explanation for the historic absence of the voices of children within communication models.

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[49] For example, initiating (e.g. questioning, explaining) and responding (e.g. reinforcement, reflecting, listening) skills (Dickson, Hargie and Morrow, 1989).

[50] For example, the person centred approach proposed by Rogers (1951), which emphasizes qualities such as unconditional positive regard (non-judgemental), genuineness (congruence) and empathic understanding.

[51] Look beyond individual skills and qualities to broader institutional and social contexts (Petrillo and Sanger, 1972; Sieh and Brentin, 1997), which might influence the dynamics of health professional-patient communication.

# CHAPTER 4: METHODOLOGY

## 4.0. Introduction

This chapter is divided into three distinct, yet interrelated, sections. Section A contextualises for the reader the historic positioning of children within research. In Section B, the philosophical and methodological assumptions underpinning this ethnographic inquiry are detailed. Section C, details my experience of *doing* ethnography in a children's ward.

## SECTION A: SOCIAL POSITIONING OF CHILDREN IN RESEARCH

### 4.1. Social Positioning of Children in Research

This section outlines the changes that have taken place in relation to the social positioning of children in research, which is comparable to how children have been socially positioned within society. While the outlook today recommends undertaking research *'with'* children, advocating for listening to children's voices and viewing children as actors and "beings" in their own right, this was not always the case. Historically, research was performed *'on'* children with the view that they were "becoming"; in a transitional immature and incompetent state *en-route* to adulthood.

#### 4.1.1. Research *'on'* children

Research 'on' children has a long history within the field of developmental psychology, which focused on (or about) how children developed and progressed towards adulthood (Hood, Kelley and Mayall, 1996). Hill, Laybourn and Borland (1996) highlighted that preference was given to standardised quantifiable methods to assess concepts, hypothesis and theories put forward by adults. Similarly, in sociology, children were objects of parental actions featuring largely within family sociology research (Hill, Laybourn and Borland, 1996, Darbyshire, MacDougall and Schiller, 2005). Children were largely invisible in their own right (Kellett, Robinson and Burr, 2004). Hogan (1998) described a model of the "child as research object", whereby children were seen as distinctive, context-free, predictable and irrelevant. The core assumptions were that childhood was a

well-regulated and standardised developmental process; children were different from adults, existed independently of time, location and social relationships and were unreliable informants with their views largely irrelevant. Similarly, anthropology was criticised for rarely examining children in their own right because the focus was on child-rearing practices with the belief that these practices were a central means by which cultural traits were transmitted (Kellett, Robinson and Burr, 2004).

Researchers within the field of education and health viewed children in the same manner; that is, unreliable as research participants, and thus relied heavily on adult proxies such as teachers, health professionals and parents (Kortesluoma, Hentinen and Nikkonen, 2003; Masson, 2004). Kortesluoma, Hentinen and Nikkonen (2003) illuminated that a great amount of what we know about children has emerged from interviewing adults. Some authors contended that adults often assume they can extrapolate memories of their own childhood and identify the concerns of children in present day realities (Coyne, 1998; Darbyshire, MacDougall and Schiller, 2005). Yet, Punch (1998; 2002a) proposed that adults often fail to remember and discard fundamentals of their childhood culture viewing their childhood from an adult-perspective. Children may view the world differently from adult proxy perspectives. Mahon et al (1996) argued that it is neither theoretically nor methodologically appropriate to rely on proxies to represent the views and experiences of children. One cannot assume adult proxies accurately represent children's experiences of their social world (Hart and Chesson, 1998). This is not to imply that adult views are invalid. Instead it affords children an opportunity to voice their concerns in matters that affect them. It recognises that all parties (children and adults) can contribute valuable insights and different knowledge (Hill, Laybourn and Borland, 1996; Hill and Tisdall, 1997; Miller, 2000). Others acknowledge that knowledge about children is incomplete unless it takes account of children's knowledge, experiences and perspectives (Kortesluoma, Hentinen and Nikkonen, 2003; Jones, 2004). To date, nursing has inadequately studied the views of children. Without the perspectives of children there is an incomplete picture of child healthcare.

### **4.1.2.** Silent voice of the child

It is possible that the silent voice of the child reflects childhood images and practices of an era where *'children should be seen and not heard'*. Adults controlled children's lives, socially excluding children in an adult-centric society. One explanation for this was the view that children were in a transitory state, growing up, on route to becoming adults (James, Jenks and Prout, 1998; Jenks, 2005; Uprichard, 2008). The contention was that children's immaturity, vulnerability and dependency meant that they were in need of adult protection resulting in reluctance to give them a voice. Carter (1998) contended that the possibility of upsetting children or disrupting their care resulted in limited support for research to explore their treatment/illness experiences. While sometimes necessary, Hart and Chesson (1998) argued that this overprotective stance limits children's potential to participate in research. This fails to realise the benefits of listening to and respecting children's views. Alderson (1995) believed such a paternalistic stance may in fact be as harmful as neglect, suggesting it is necessary to balance risk against the harm of failing to consult children. Further explanations for failure to consult children include the belief that children are inaccurate informants (due to poor memories and the desire to please adults), developmentally immature, lack understanding and competence to take part, with many methodological and ethical challenges (Hart, 1992; Mahon et al, 1996; Carter, 1998; Coyne, 1998; Bricher, 1999a; Miller, 2000; Scott, 2000; Smyth, 2001; Masson, 2004). Hart (1992) believed that children as young as five years old could provide highly accurate information and while children may not possess the same communication abilities as adults this does not mean that information from children is invalid. Contrarily, it signifies that we need to be sensitive to children's different developmental needs and find methods to maximise their ability to speak about matters concerning them.

### **4.1.3.** Research *'with'* children

The last 30 years have witnessed a paradigm shift of thought within the Social Sciences. In 1973, Hardman noted the 'silent voice of children' and called for the study of children in their own right (Hardman, 1973). This stimulated the development of interest in the social studies of childhood with children now receiving increased recognition as a distinct social group (James and Prout, 1997; Kellett, Robinson and Burr, 2004; James and James,

2004). Children are no longer perceived to be passive recipients of adult socialisation but rather active in structuring and making sense of life as they experience it (James, Jenks and Prout, 1998; Woodhead, 1999; Woodhead, 2003a&b). These academic reorientations parallel societies changing views of childhood (Hill, Laybourn and Borland, 1996).

Understanding children and childhood requires listening attentively to children's agendas and participating with them in the research process (Hood, Kelley and Mayall, 1996; Mayall, 1996). This has led to a growing number of studies, which aim to explore the perceptions of children themselves,[52] and advocate for a movement towards children's participation in service design, delivery and evaluation; with the emergence of national and international laws and policies outlining children's participatory rights (previously elluded to in Section 2.4). As a consequence, a wealth of participatory research methods (Boyden and Ennew, 1997; McCabe and Horsley, 2008) and terminology such as social action (Jones, 2004), participatory (action) research (Whyte, 1990; Hart, 1992; Kirby, 1999) and participatory rural appraisal (Punch, 2002a) has emerged.

Alderson (2004) highlighted that children's involvement in research has evolved from being objects of study, to sharing their own insights as active participants and even undertaking research themselves as co-researchers. There are various ways, stages and levels at which children can be involved (Hart, 1992; Kirby, 1999; Fajerman and Treseder, 2000). Punch (2002a) affirmed that it may not be possible for children to participate fully in all stages of research in every situation, with the level of participation dependent upon a number of factors (e.g. research context, research questions, researcher attitude/behaviour, children and age). In this study, children were involved at an earlier stage in a multidisciplinary advisory group (see Section 4.8) and in the production and piloting of information sheets, consent forms and participatory tools (see Section 4.10.1.3 and 4.12.3.2).

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[52] For example, see Mayall (1994), Polkki, Pietila and Rissanen (1999), Nesbitt (2000), Carter, Lambrenos and Thursfield (2002), Wesslen, Sepp and Fjellstrom (2002), Hart, Bishop and Truby (2002), Kennedy et al (2002), and Polkki, Pietila and Vehvilainen-Julkunen (2003).

Levels of involvement often equate with the amount of power adults and children share. Greig and Taylor (1999:148) argued that while all researchers are in a potentially powerful position, the "relative power of adults to children makes this a double edged sword when involving children as research subjects". Coad and Lewis (2004) asserted that a key challenge lies in redressing the power imbalance that exists between adult researcher and child participant. Suggested strategies for redressing adult researcher-child participant power imbalance include, acknowledgement during data collection, analysis and write up (Balen et al, 2000/2001), becoming one of the children (Mandell, 1988; Cree, Kay and Tisdall, 2002), and the employment of a child-centred[53] approach using a variety of imaginative tools (Mahon et al, 1996; Mauthner, 1997; Punch, 2002a&b). Participatory techniques employed within this study were the draw and write technique and a stick-a-star quiz, which I developed and employed to focus specifically on different aspects of communication (Section 4.12.3).

It is important to consider the way researchers perceive childhood and the status of children in society because this influences the methods chosen, the interpretation of data generated and thus how children and childhood will be understood (James, Jenks and Prout, 1998; Punch, 1998; Harden et al, 2000). James, Jenks and Prout (1998) described four ways of seeing children, *developing*, *tribal*, *adult* and *social* child. First, if we see children as *developing* we would predominately utilise experimental designs because we would undervalue children's competence. Next, if we see children as inhabiting an autonomous world separate to us, adults, we would prevalently use participant observations (*tribal* child). Thirdly, we would employ routine adult methodologies if we viewed children as competent to participate in a shared adult-centred world (child as *adult*). Finally, James and others offer a solution in unfolding the *social* child, a view this thesis upholds. The *social* child is viewed as comparable to adults but with different communicative competencies. Punch (1998; 2002a) expresses similar sentiments when considering whether research with children is different or similar to that with adults.

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[53] Punch (1998; 2002a) suggested a change in terminology from condescending 'child-friendly' to 'research-friendly' or 'person-friendly' techniques and combining traditional adult with innovative 'child/participant-friendly' methods.

Thus, to take account of children's vulnerability, immaturity and developmental levels, it is vital to employ methods to maximise children's ability to express their views and explore ethics to prevent exploitation. Thomas and O'Kane (1998) advocated that using an approach that gives children control over the research process and methods can augment validity, reliability and ethical acceptability of research with children. The trial for researchers is to find "new ways of engaging children in research and development and application of methods, which involve negotiation rather than imposition" (Hill, Laybourn and Borland, 1996:130).

Research for this thesis draws on the paradigm of the *new* sociology of childhood which offers guiding principles for understanding children and childhood (James and Prout, 1990; 1997). The new orthodoxy in childhood research (and central to the paradigm for the study of childhood), *ethnography*, is an appropriate methodological approach to engage with children because it allows children a more direct voice, recognising children as individuals in their own right (James and Prout, 1997; James, 2001). Ethnography permits the view of children as competent interpreters of the social world and thus active research participants (James, 2001).

In summary, this section provided an overview of the changes that have taken place in the social positioning of children in research; which equates with movements taking place in the social positioning of children in society. The last twenty years has seen a paradigm shift in childhood research with children's positioning evolving from unknowing objects to aware subjects and active participants. Historically, the norm was to employ parents and health professionals as proxies to represent children's voices, based on the concern for children's welfare, vulnerability, and ability to take part in the research process. Today children are valued as competent research participants. The current belief is that to understand children and childhood there is the need to listen attentively to children's agendas and participate with them in the research process. However, it is crucial to employ methods that take cognisance of children's vulnerability, immaturity and developmental stages, in addition to their autonomy, thereby maximising their ability to express their views openly. Ethnography is fundamental to understanding how children

make sense of their social world. It allows for an in-depth, naturalistic, holistic, creative and flexible child-centred investigation, which does not artificially separate context and person. In the following section, I will outline the philosophical and methodological assumptions underpinning this ethnographic inquiry.

## SECTION B: PHILOSOPHICAL AND METHODOLOGICAL ASSUMPTIONS

### 4.2. Philosophical and Methodological Assumptions

Often described as the building blocks of research, ontology and epistemology are "to research what 'footings' are to a house: they form the foundations of the whole edifice" (Grix, 2004:57). Uncovering these foundations is no easy task. Much of the difficulty I encountered was lack of clarity surrounding the interchangeable use of terminology and classification of ontology and epistemology.[54] Perhaps the difficulty lies in clearly demarcating a boundary between ontology and epistemology, each being inextricably woven together (Crotty, 1998; Guba and Lincoln, 2006). Furthermore, discussions within ethnography predominantly focus on the process and product of doing ethnographic fieldwork; with dialect surrounding ontological and epistemological assumptions often limited. As a result, of this dearth and lack of clarity, Appleton and King (2002) argued that it is imperative to outline ones underlying assumptions. This section presents the philosophical assumptions informing this ethnographic inquiry. The plan is not to rehearse long debated and documented issues, rather to present my interpretation which directly influenced this study.

#### 4.2.1. Interpretivism

The longstanding conflict that exists between the two competing paradigms (qualitative and quantitative) of social research is as a result of rivalling philosophical positions, nominally positivism *versus* interpretivism (often simultaneously referred to as naturalism); each of which view the world through a different lens. Essentially the

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[54] For example, Robson (2002) states that relativism is often referred to as constructivist, naturalistic and interpretive, whereas Crotty (1998) categorises relativism as ontology and constructivism as epistemology embodied within an interpretivist theoretical perspective.

differing perspectives, marked by a profusion of 'isms' and 'ologies', reflect the ongoing debates surrounding what the concept of 'truth' entails; which research tries to discover. These debates of what is true and real are ontological debates, with ontology referring to; what is; the nature of existence; of being; the structure of social reality (Wainwright, 1997; Crotty, 1998; Grix, 2004; Guba and Lincoln, 2006). Epistemology refers to a way of knowing, a way of understanding and explaining what exits (Wainwright, 1997; Crotty, 1998; Grix, 2004; Guba and Lincoln, 2006).

Positivists believe that it is possible to discover and know about universal truths with absolute certainty. Reality exists independent of human consciousness and knowledge can only be of value if it represents the truth (Kim, 1993; Booth, Kenrick and Woods, 1997; Wainwright, 1997; Grix, 2004). A consensual tangible external reality exists that can be fully known about through experience with it (Lincoln and Guba, 1985; Playle, 1995). The scientific method is central to positivism where scientific theories are subject to standardised tests, which can confirm or falsify with certainty[55] (Booth, Kenrick and Woods, 1997; Hammersley and Atkinson, 2007 [1995]). Such contentions reflect naïve/dogmatic/scientific realism (ontology) and an objectivist epistemology (Grix, 2004; Guba and Lincoln, 2006). However, objectivists are not without their critics and an example of this, expressed in the words of Speziale and Carpenter (2007:4), is:

> "There is much debate about the relative value of information that is derived from a purely objective standpoint when it comes to human phenomena within a social context. Concepts of objectivity, reduction, manipulation, which are fundamental to empirical science, defy the authentic fiber of humans and their social interactions."

Many embrace ethnography on the basis that positivism fails to encapsulate the true nature of human social behaviour because it mainly focuses on what people report in artificially constructed settings, as opposed to what actually happens in real life settings (Atkinson and Hammersley, 1994). Playle (1995) goes so far as to say positivism dehumanises both the research process and the subjects of research because it promotes a detached and cold quest for objective scientific knowledge. In the following quotation

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[55] This reflects empiricism where the basis of quality research was the proper application of a set of procedures or methods isolated from human values and judgements.

Malinowski (1922:17) powerfully portrayed the lack of humanness arguably inherent within objectivist inquiries:

> "In certain results of scientific work – especially that which has been called "survey work" – we are given an excellent skeleton, so to speak, of the tribal constitution, but it lacks flesh and blood. We learn much about the framework of their society, but within it, we cannot perceive or imagine the realities of human life, the even flow of everyday events, the occasional ripples of excitement over a feast, or ceremony, or some singular occurrence."

In contrast to positivism, naturalism/interpretivism emerged in an attempt to understand *"culturally derived and historically situated interpretations of the social life-world"* (Crotty, 1998:67 original italics). Interpretivism is concerned with understanding, as opposed to explaining or arriving at knowledge of prediction (causality) (Kim, 1993; Schwandt, 2003). Although, Crotty (1998) highlighted that in some of Weber's historical thinking, from which *Verstehen* (understanding) emerged, he wanted to explain as well as understand. However, according to Crotty (1998) any emphasis on explanation appears to have dissolved. Geertz (1973:5), also drawing on the work of Weber, stated:

> "Believing with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning."

As illustrated in the above quotation, interpretivist philosophies are primarily concerned with grasping the *meanings* that constitute social actions (Schwandt, 2003). In order to do this, interpretivists must *empathetically identify with actors* to understand the meanings they attribute to their experiences (Schwandt, 2003).[56]

### **4.2.2.** Social constructionism

Beliefs expressed within an interpretivist perspective reflect a relative ontology (Kim, 1993; Grix, 2004). Relativist believe that no external objective reality exits independent of human consciousness, knowledge can be of value even though it may not represent absolute truth, the nature of knowledge or reality is socially constructed, thus reflects the

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[56] This, for me, appeared to neglect two things. Are understanding and meaning solely situated within individual actor's cognitions? What about contextualisation or the culturally derived and historical interpretations referred to by Crotty? What of me, the researcher? Have we come full circle from objectivity to subjectivity, focusing solely on the 'actors' understandings and meanings?

nature and circumstances of its production (Robson, 2002; Grix, 2004). Here, both the nature of reality and the nature of knowledge are constructions from within the minds of individuals, resulting in a diversity of views, influenced by culture (Robson, 2002). Relativism is the ontology that links with the epistemology constructivism, with constructivist viewing reality as local and specific – relative (Lincoln, 1990; Kim, 1993; Denzin and Lincoln, 2003; Guba and Lincoln, 2006).

Within the constructionist perspective, knowledge (and *all* reality) is socially constructed and discovered through researcher-researched interactions and relationships (Berger and Luckmann, 1967;[57] Smith, 1990; Lincoln, 1990). Constructionists reject the view that knowledge exists independently of consciousness (Smith, 1990; Wainwright, 1997). There is no objective truth to be discovered (Smith, 1990; Robson, 2002). Knowledge is constructions of the human mind (Kim, 1993). Constructions help people explain and make sense of their experiences, each in their own different way (Schwandt, 1994; Crotty, 1998; Appleton and King, 2002). Thus, social reality exists as individuals experience it and assign meaning to it (Appleton and King, 2002). People assign meaning to reality through a continuous process of social interaction, interpersonal communication and negotiation (Schwandt, 1994; Appleton and King, 2002). As a result, knowledge *is "constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context"* (Crotty, 1998:42 original italics). Thus, knowledge discovery is a process of construction, in terms of how people construct reality, through their interpretations of it and their actions based on those interpretations (Atkinson and Hammersley, 1994). The researchers' aim is to understand these multiple social constructions of meaning and knowledge, thus acquiring multiple perspectives (Appleton and King, 2002; Robson, 2002). Building on this, Crotty (1998:54) highlighted:

> "While humans may be described, in constructionist spirit, as engaging with their world and making sense of it, such a description is misleading if it is not set in a genuinely historical and social perspective."

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[57] In agreement with Berger and Luckmann (1967:37), "I cannot exist in everyday life without continually interacting and communicating with others. I also know, of course, that others have a perspective on this common world that is not identical with mine. My 'here' is not their 'there'. My 'now' does not fully overlap with theirs. All the same, I know that I live with them in a common world."

Therefore, it is crucial to consider contextual factors to understand the holistic picture (Lincoln and Guba, 1985; Appleton and King, 2002). Contextual circumstances (subjective, historical, cultural or institutional) shape knowledge construction and contextualisation helps with impartiality (Kim, 1993).

It is acknowledged that the context cannot be studied in isolation of the researcher with the researcher being part of the social world he/she studies (Lincoln and Guba, 1985; Guba and Lincoln, 2006; Hammersley and Atkinson, 2007). An interactive monism between researched and researcher replaces the subjective-objective dualism of positivism (Lincoln, 1990; Guba and Lincoln, 2006). This was not always the case. Historically, the aim was to minimise researchers' values in order to produce findings that were truly independent of any particular value stance. Indeed, much of this doctrine of naïve realism was deep-rooted in ancient ethnography, with the proposal to study, as far as possible, the social world in its natural state undisturbed by researcher (Hammersley and Atkinson, 2007). The contention was that the adoption of an ethnographic approach would enable the researcher to get closer to social reality than other methods (Hammersley, 1992). Here a paradox appears within ethnography between naturalistic and constructionist perspectives (Atkinson and Hammersley, 1994). This illustrates that not only are there ontological and epistemological challenges evident across different research paradigms, such conflicts also emerge within paradigms themselves.

In the present day, the quest for value neutrality is suspect in the wake of reflexivity, which acknowledges that researchers' cannot avoid having an effect on the social phenomena they study. The researchers' orientation is "shaped by their socio-historical locations, including the values and interests that these locations confer upon them" (Hammersley and Atkinson, 2007:15). Thus, rather than attempting to produce findings that are completely free of any value stance researchers must monitor and reflect upon the products of their participation in the social world (Hammersley and Atkinson, 2007). Subjectivity has seen a transformation from problem to opportunity (Finlay, 2003). I see myself as inherently part of the process and product of this thesis, which has ultimately

arisen from a process of prolonged interaction between hospitalised children and myself, but also influenced by my socio-cultural and historical background (see Section 8.6).

It was partly this relativist constructivist perspective that informed my thinking. I could equate with critics of naïve realism on the grounds one cannot claim to know the absolute truth with certainty and more strongly with the contention that I, the researcher, am also part of this social reality, thus the notion of subjective reality is incoherent. In spite of this, I encountered two difficulties, first, in relation to reality and second, in relation to causality. I will deal with each of these in turn.

*Truth: real or relative*

One, if I engaged with children with the contention that there was some doubt about the truth of what they were relaying to me, whether absolute or partial, then I would be in some way undermining their views. This negated with my personal perspective and the ultimate purpose of this research, to hear and represent the voice of the child. While I did believe that truth beyond all certainty was difficult to achieve, as it is not universal, I believed in multiple truths that were context specific and changed over time. My thoughts appeared to transverse both realism and relativism.[58] The fact that the researcher is part of the research and that one cannot know 'truth' with absolute certainty does not undermine the notion of realism. In the nomenclature of Crotty (1998:63), "social constructionism is at once realist and relativist. To say that meaningful reality is socially constructed is not to say that it is not real".

Atkinson and Hammersley (1994) suggested that we must not be misled in assuming we are merely faced with a dichotomous choice between a single oppressive conception of science, that of realism, and a uniquely liberating alternative, that of relativism. Relativism is not the only alternative to naïve realism.[59] Hammersley (1992:50) went as far as to suggest; "there is a great danger of backing ourselves into a corner by deploying

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[58] Routinely portrayed as bipolar, realism is generally associated with positivist objectivist thinking while relativism is associated with interpretivist constructivist perspectives (Kim, 1993).
[59] Lincoln and Guba (1985) highlight four levels of reality, objective, perceived, constructed, and created.

a dichotomy which obscures the wide range of epistemological positions available". The solution, according to Hammersley (1992), is the deployment of more subtle forms of realism. Subtle realism shares with relativism the opinion that all knowledge is socially constructed and reliant on cultural assumptions. On the other hand, subtle realism rejects the idea that knowledge is mind dependent, believing that knowledge can exist independently.[60] However, it abandons the notion that knowledge, and thus truth/reality, can be knowable with certainty. Rather, it proposes that the criterion *beyond reasonable doubt* or *warranted assert-ability* (that is what is reasonable to believe and assert) are employed to judge knowledge claims (Hammersley, 1992; Johnson and Onwuegbuzie, 2004).

*Causality*

The second difficulty I encountered related to causality. For instance, a constructivist viewpoint contends that the concept of causality is misleading, simplistic, and out of date, with the process of assembling meanings not simply taking place in a linear fashion (Appleton and King, 2002). Indeed, some argue constructivism produces superficial understanding of individual actions (Wainwright, 1997). This ignores social structures within society that constrain and enable the actions of individuals (and influence individual perceptions of reality) resulting in analytical superficiality and loss of a critical edge (Porter and Ryan, 1996; Wainwright, 1997; McEvoy and Richards, 2006). However, I found myself attempting to explain what was causing the different positioning of children in the communication process. Within the context of this study, I sought to understand and interpret the daily life of children in the context of hospital, and in doing so sought to give them a voice. However, I could not neglect my position and experience as a nurse. Thus, in order to advance nursing practice there was the need to consider children's voices within the context of localised institutional and wider societal practices,

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[60] The discrepancy appears to be with the term independent, is reality/knowledge independent or dependent of mind? Hammersley (1992:51) clarifies: "making a claim does not itself change relevant aspects of reality in such a way as to make the claim true (or false)...for the most part reality is independent of the claims that social researchers make about it".

in an attempt to explain why what was happening, in relation to communication practices between children and health professionals, was. [61]

Porter and Ryan (1996) offer some explanation on what was happening here: a debate between *etic* and *emic* perspectives.[62] The *emic* perspective receives credence over the *etic*, with the view that an *etic* focus would invalidly impose the scientist subjective understandings on the research participants. If this is the case, such dismissal of the *etic*, neglects to take account of larger scale matters (Porter and Ryan, 1996). It is possible for nursing research to give attention to both *emic* and *etic* perspectives by broadening epistemological boundaries and adopting a critical realist perspective (Porter and Ryan, 1996).

McEvoy and Richards (2006) highlighted that critical realism goes beyond merely describing beliefs or experiences of social actors to develop deeper levels of explanations and understanding. Critical realists do not devalue interpretivism, instead they recognise the interdependence of human agency and social structures (McEvoy and Richards, 2003; McEvoy and Richards, 2006).[63] A two-way relationship exists between social structures and individual actors. For instance, individual actions are *influenced* by the enablements and constraints imposed upon them by social structures. In turn, individual actions *influence* social structures by either maintaining or transforming them. The aim of the researcher is to ascertain patterns of social behaviour and then to identify the *tendencies* generated by existing structures that, may, must, or could, have caused those patterns to occur (Porter and Ryan, 1996; McEvoy and Richards, 2006). The outcome according to Porter and Ryan (1996:415) is:

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[61] This will become evident later when I present and discuss the findings, but briefly, to put into context, I focus the findings at a *micro* level, based on children's perspectives of the process of communication that took place between them and health professionals. I expand the debate to a *marco* level by discussing the findings at a broader and more in-depth level. This involved taking child participants constructed meanings and broadening them to theories beyond their cultural experience (Carspecken, 1996).

[62] *Emic* refers to participant's (insiders) point of view or perspective of reality. *Etic* refers to the researcher's (outsiders) point of view, what he or she observes through fieldwork and his/her scientific explanation of reality (Boyle, 1994; Fetterman, 1998).

[63] In view of my earlier argument about the dichotomous nature of realism and relativism, critical realism combines a realist ontology with a relativist epistemology (McEvoy and Richards, 2003)

> "Exposure of social structures and the restraints and enablements that they impose upon our freedom to act in our own interests provides us with knowledge that can be used in attempts to improve the structural organisation of society."

One potential criticism hurdled towards critical realism, as cited by Porter and Ryan, is the potential over-reliance on an *etic* perspective. In light of this, Porter and Ryan (1996) contend that it is necessary to combine the critical realist philosophy with an interpretive model (such as ethnography), which would allow for uncovering the *emic* perspective.

However, ethnography aims not only to collect information from an *emic* internal perspective, both also to make sense of data from an *etic* external social science perspective (Robertson and Boyle, 1984;[64] Fetterman, 1998). Thus, returning to further explore and reflect on social constructionism, constructionism views meanings as "at once objective and subjective, their objectivity and subjectivity being indissolubly bound up with each other" (Crotty, 1998:48).[65] Perhaps what was happening here was a muddling between the usage and interpretation of the terms constructivism and social constructionism. According to Crotty (1998:58), ***constructivism*** refers to the "meaning-making activity of the individual mind", "the unique experience of each of us", whereas ***constructionism*** refers to the "collective generation [and transmission] of meaning" and ***'social' constructionism*** "emphasises the hold our culture has on us". Crotty (1998:58) highlighted the *critical spirit* inherent within social constructionism in the following quotation:

> "It [constructivism] suggests that each one's way of making sense of the world is as valid and worthy of respect as any other, thereby tending to scotch any hint of a critical spirit. On the other hand, social constructionism emphasises the hold our culture has on us: it shapes the way in which we see things……and gives us a quite definite view of the world…..it can be said that constructivism tends to resist the critical spirit, while constructionism tends to foster it."

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[64] Robertson and Boyle (1984) highlight that the epistemology upon which an ethnography is based is determined by the ethnographer in terms of either an *etic* or *emic* focus, with most utilising an eclectic research style drawing from both *etic* and *emic* epistemologies. They go on to state that while the distinction between *etic* and *emic* is crucial in ethnographies, this does not mean a higher or lower scientific status for either *etic* or *emic* perspectives.

[65] Pouliot (2007) suggested the use of the term *sobjectivism* as a methodology specifically geared to constructivist style of reasoning, with the need to develop not only objectified (distant) but also subjective (near) knowledge about social life. Sojectivism follows a stepwise logic from the recovery of subjective meaning, to their objectivism through contextualisation and historicisation.

As Geertz (1973:14) highlighted:

> "Culture is not a power, something to which social events, behaviours, institutions, or processes can be casually attributed; it is a context, something within which they can be intelligibly – that is, thickly described."

Owing to its assortment of meanings (as will be displayed next), ethnography, is not often utilised in a wholly orthodox fashion, nor does it fall under the auspices of one core epistemological belief. In the preceding section I attempted to give some indication of my ontological and epistemological orientations. A social constructionist epistemology and a subtly real ontology underpin this ethnographic inquiry. This means that I view knowledge and reality as socially constructed and discovered through researcher-researched interactions and relationships. I believe that knowledge can exit independently of mind, but we can only come to know about it partially and judge it by reasonable assert-ability. Next, I will outline what I take the term *ethnography* to mean, in order to promote a clearer vision of the methodological process employed.

### 4.3. Methodological Assumptions: Ethnography

One often talks of the emotional labour within ethnography, especially in relation to dealing with fear, anxiety and stress within the field. However, for me, the fear, anxiety and stress extended far beyond the field. It began with, and continues to raise, the ultimate question; what is ethnography? As Agar (1996:2) highlighted "we're closer than we were in 1980, but we're still in the early steps of the dialectic dance of exploring what ethnography is and how it works". As will be seen later, it is often easier to state what it is ethnographers do than to come up with a single definition of what ethnography entails. In its literal translation, ethnography refers to writing, describing, or painting a picture (graph); about particular folks or people (ethno) (Agar, 1986; LeCompte and Preissle, 1993; Boyle, 1994; Wolcott, 1999; Brink and Edgecombe, 2003). It is of no surprise that there is no standard consensual definition because there are many variations and interpretations of ethnography (Boyle, 1994). Therefore, it is impossible to outline one

core definition that would encapsulate all of its [ethnography] meanings in all contexts (Hammersley and Atkinson, 2007).[66]

Ethnography's long renowned intricate history is one explanation for its ill-defined singular meaning (Hammersley and Atkinson, 2007). Ethnography developed as a methodology mainly within the disciplines of anthropology and sociology (Mackenzie, 1994; Laugharne, 1995). For instance, within the 19th century cultural anthropology, ethnography developed as a means to understand and describe tribal cultures (Malowinski, 1922). Traditionally, anthropologists lived among these 'other' cultures for months and years. In the 1920s to 1950s sociologists at the University of Chicago adopted anthropological traditions to study patterns of city social life (Hammersley and Atkinson, 2007 [1995]). In recent times, ethnography has further diversified within and across multiple disciplines by anthropologists (Bluebond-Langner, 1996); sociologists (Emond, 2005); educationalists (Sirja-Blatchford and Sirja-Blatchford, 2001); midwives (Hunt and Symonds, 1995); nurses (Soderback, 1999; Tinney, 2008) and medics (Zaman, 2008), to mention a few. As a result, of this diversification ethnography has become re-contextualised in various ways. Appendix 4 illustrates a number of diverse definitions of ethnography from different perspectives. One distinct change is that in times past traditional ethnographies predominantly studied exotic, overseas, isolated and strange cultural worlds. Whereas, in more contemporary times ethnographies have become preoccupied with local cultures, nearer home, in an attempt to gain understanding of cultural behaviours, activities, and beliefs within more familiar settings (Boyle, 1994; Atkinson and Pugley, 2005). Another potential source of confusion possibly centres on the diverse use of interchangeable terminology, such as ethnography, qualitative research, field study, fieldwork, case study,[67] descriptive research, naturalistic research, participant

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[66] Savage (2006:384) contended that "the absence of a single fixed understanding of ethnography has probably contributed to its under-utilisation in healthcare research".

[67] Indeed, at the outset of this study I embraced a case study strategy but then moved to an ethnographic approach because it acknowledges wider socio-cultural factors stretching beyond the boundaries of the immediate communication process, the children's ward and even the hospital. I considered it vital to explore the wider family, community, society and cultural influences in an attempt to explain themes emanating from the interactive processes between children, health professionals and parents.

observation, and so on. Despite this, there are essentially two criteria at the core of ethnography. It is a *field-oriented activity* and it has *cultural interpretations.*

The hallmark of cultural anthropology, *doing fieldwork*, remains the commonest feature, and broadest application of ethnographic work (Wolcott, 1999). The majority agree that ethnography involves the researcher gathering information about people firsthand, through observing and questioning participants (Spradley, 1980; Robertson and Boyle, 1984; Baillie, 1995; Fetterman, 1998; Hume and Mulcock, 2004), as the following select quotations (the first from a sociological perspective and the second an anthropologists) illustrate.

> "Ethnography usually involves the researcher participating, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, and/or asking questions through informal and formal interviews, collecting documents and artefacts – in fact, gathering whatever data are available to throw light on the issues that are the emerging focus of the inquiry" (Hammersley and Atkinson, 2007: 3).

> "True, we hear reference to an "ethnographic mystique" but there is little mystery in an approach that encourages one to experience the ways of a group firsthand, to supplement what one is able to observe with interviewing to learn what those in the group make of their experience, and further to supplement what can be learned firsthand with information gathered or materials prepared by others" (Wolcott, 1999: 62).

The second main (and broad) concept lying at the heart of ethnographic work is *cultural patterning and interpretation* (Spradley, 1980; Baillie, 1995; Fetterman, 1998; Wolcott, 1999; Hammersley and Atkinson, 2007). Although, the centrality of culture has waned with the changing nature of ethnographic work (Wolcott, 1990), arguably the necessity to learn about culture was most understandable in cases of studying societies other than our own (Hammersley and Atkinson, 2007). Although Wolcott (1990:50) argued "there is no ethnography until culture makes an entry, no matter how tenuously". At a later point, he clarified this by highlighting that this can be, but does not have to be, the mission.

> "This is not to say that an explicit cultural framework must be rigorously imposed on every study, but it does mean that to be ethnographic, a study must provide the kind of account of human social activity out of which cultural patterning can be" (Wolcott, 1999: 68).

Wolcott (1999:68) went on to define culture as "an abstraction, a perspective for studying human behaviour that gives particular attention to ("privileges," in today's lexicon)

acquired social behaviour". The emphasis is on describing and understanding regularities of *human social behaviour* that implicate cultural processes. Therefore, while ethnography fittingly aims to describe a particular group's culture, it also encompasses other less ambitious goals such as exploring patterns and processes of human social behaviours and presenting detailed contextualised cases (Wolcott, 1990; Emerson, Fretz and Shaw, 2001). Furthermore, many different layers of cultural knowledge exist, with the value of ethnography "founded upon the existence of such variations in cultural patterns across and within societies, and their significance for understanding social processes" (Hammersley and Atkinson, 2007:9).

This is the perspective I assume within the context of this thesis. The ultimate goal of this study is to explore, describe and interpret patterns of social behaviours related to the process of communication that takes place between children and health professionals on the children's ward. The intention is to represent implicitly and critically interpret local cultural practices of the children's ward in order to contextualise these social behaviours locally and universally. For as Savage (2006:385) states:

> "It is arguably the way in which ethnography makes links between the micro and the macro, between everyday action or interaction and wider cultural formations through its emphasis on *context*, that most clearly distinguishes ethnography from other approaches (and makes it particularly valuable for researching health care issues)."

The different cultural orientations implicit within the above argument might be explained by the actual scope of the ethnographic study. Spradley (1980) clearly outlines the scope of ethnographic research, placing it along a continuum form macro to micro level.[68] For instance, the culture described might range from a small tribal group in an exotic land to a small classroom in middle-class suburbia (Fetterman, 1998). Through diversification and re-contextualisation across disciplines ethnographies have shrunk in scale from 'macro' studies covering holistic cultures over long periods to 'micro' or mini short focused studies over a number of weeks and/or months rather than years.

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[68] At one end are micro-ethnographies that examine a single situation, multiple social situations or a single social institution. At the other end of the continuum are macro-ethnographies that examine multiple communities and a complex society (Spradley, 1980).

Micro-ethnographies are also known as focused or specific ethnographies because they zone in on particular behaviours within a particular setting as opposed to attempting to portray a cultural system in its entirety (Wolcott, 1990). Some would argue that what is actually taking place is the application or borrowing of ethnographic techniques as opposed to 'true' ethnography in its authentic, time-honoured, traditional sense. Boyle (1994) outlines two main "taxomomies" of ethnographies, *processual* and *binary.* For the context of this study, I am concerned with processual ethnographies, which Boyle (1994:170) defines as "ethnographies that describe some aspects of social processes" and of which there are four distinct sub-types. These include, *holistic*, *particularistic*, *cross-sectional*, and *ethnohistorical.* In terms of this study, I am interested in the particularistic sub-type, though, I also want to draw attention to how the term holism is utilised. Particularistic simply means applying an ethnographic approach to processes within small groups, isolatable human group, any social unit and/or parts of a culture (Boyle, 1994). This is similar to the mini-ethnographies proposed by Spradley (1980). According to Boyle (1994) holistic ethnographies, also named classical, focus on describing entire social groups and cultural systems. However, this does not mean that an ethnography that does not study an entire social group or cultural system, is not, or cannot be, holistic. A particularistic ethnography could provide a holistic - rounded, comprehensive, contextualised - account of the focused topic or setting under investigation. Yet, portraying a holistic picture does not mean that the picture portrayed is a complete one. Geertz's (1973) concept of *thick description* implies that a total picture of the social setting, context or situation be presented. However, at best the picture painted can only be partial, inferential and partisan (Agar, 1986; Wolcott, 1999; Hammersley, 2008). This is the view proposed within this mini-contextualised ethnographic inquiry.

### **4.3.1.** Ethnographic characteristics

In applying ethnographic techniques it is imperative to consider some of its trademark features, for instance, naturalism, holism, contextualisation, unstructured state, multi-data sources, usage of both *emic* and *etic* data, reflexivity, focus on small cases and the interpretation of the meanings and functions of human actions and institutional practices

(Boyle, 1994; Hammersley and Atkinson, 2007).[69] I integrate some of these elements in the following discussion.

Ethnography relies on the collection of data in natural environments or real-world settings. Naturalism refers to the fact that the researcher must go to places where people are, or as more traditionally stated they must 'enter the field'.[70] In the following picturesque quotation, Wolcott (1999:43) eloquently portrayed the emblematic image of an ethnographer arriving in a native land:

> "Ethnography is, for many, a rather highly romanticized (and technically impossible) idea about "living one's way into a culture.....An idealised image of someone outfitted in safari suit and pith helmet stepping onto the shore and into the center of a circle of huts, with camera, binoculars, and notebook at the ready."

When in the field the ethnographer assumes an apprenticeship type role; learning about[71] and participating (to varying degrees) in the mundane everyday activities and observing the actions and behaviours of the people within the setting (Boyle, 1994; Fetterman, 1998; Hume and Mulcock, 2004; Hammersley, 2008). The contextualisation of these activities and behaviours is extremely important, with the underlying belief that one cannot study human behaviour in isolation of, or independently from, the environment or context in which it occurs (Lincoln and Guba, 1985; Baillie, 1995; Hammersley and Atkinson, 2007 [1995]). Furthermore, contextualising the data enables the researcher to place it within a larger perspective and capture a more holistic view (Boyle, 1994). This involves extensive fieldwork in naturalistic settings for prolonged time-periods, which means the researcher will have direct personal face-to-face contact with participants (Robertson and Boyle, 1984; Boyle, 1994; Christensen, 2004; MacPhail; 2004). This enables capturing more than a *snapshot* and assists with recognising routine, repeated and patterned social practices and processes (MacPhail, 2004).

By being there, in the field, the ethnographer is the prime instrument of data collection (Robertson and Boyle, 1984; Lincoln and Guba, 1985; Wolcott, 1999; Hume and

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[69] See Appendix 5 for a list of some key characteristics of ethnographic studies.
[70] As opposed to, participants entering artificially constructed settings for structured interviews.
[71] Also learning from people in the setting, not just learning about them (Spradley, 1980).

Mulcock, 2004; Hammersley and Atkinson, 2007 [1995]). Therefore, to fulfill this role the ethnographer embraces multiple techniques in order to gather data, most notably participant observations, formal and/or informal interviews, documents and artifacts (as illustrated through the previous quotations on page 84).[72]

Many draw on the original work of Malinowski (1922:25) arguing that the central goal of ethnography is "to grasp the native's point of view, his relation to life, to realise his vision of his world". However, this predominant *emic* perspective, which was prevalent in historic and traditional times (to understand the exotic primitive other), neglects to acknowledge the researchers *presence* and *etic* perspective.[73] As previously outlined, the nature of reality is a product of multiple perceptions including that of the researcher and produced by interaction between researcher (*etic*) and participants (*emic*). Indeed, as the anthropologist Geertz (1973:9) wrote on interpretive cultures "what we call our data are really our own constructions of other people's constructions of what they and their compatriots are up to". Thus, the employment of multi-modal methods captures rich and diverse data from both *etic* and *emic* perspectives. The interface between observations and conversations results in the reflexive nature of ethnography (Boyle, 1994; Soderback, 1999). Reflexivity acknowledges the presence of the researcher alongside the social actors (Lipson, 1991).

> "Both views are important in helping the ethnographer understand why members of that particular group do what they do, and both are necessary if the ethnographer is to understand and accurately describe situations and behaviours. Both views help the ethnographer develop conceptual or theoretical interpretations" (Boyle, 1994:166).

For that reason, the ethnographer tries to make sense of the data in terms of both the participant's *emic* perspective and their own *etic* and scientific analytic perspective (Boyle, 1994; Hume and Mulcock, 2004). This is the perspective taken in this thesis. It is "co-constructed - a joint product of the participants, researcher and their relationship"

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[72] Hammersley (2008) suggested one should be innovative in thinking about the sources of potential data and draw on range of different sources to answer questions asked.

[73] Some anthropologists who are interested in merely exploring the *emic* perspective tend to use cognitive/ethno-science to collect/analyse data. These often result in taxonomies, componential/domain analysis or cultural themes, such as the work of Spradley and Agar (Boyle, 1994).

(Finlay, 2003:5). I draw on data from the inside child patient perspective (*emic*) and add to this my outside *etic* perspective. This adds to the holism referred to previously.

The focus is on small numbers of cases, with a case equating to a single setting or group of people.[74] The aim is to achieve depth rather than breadth. Data collection is unstructured in two ways. Firstly, there is not always a fixed and detailed research design at the outset of the study. Often what was set out will have to be 'rethought' (Hammersley, 2008).[75] Secondly, there are no pre-set categories or orderly schedules incorporated into the data collection process for guiding and interpreting what people say or do (Hammersley and Atkinson, 2007 [1995]).[76] The data analysis process generates these. Data analysis involves the interpretation of the meanings, functions and consequences of human actions and institutional practices, and the implication of these within local and broader contexts (Savage, 2006; Hammersley and Atkinson, 2007). However, as Wolcott (1999:70) asserted there is the necessity to employ an underlying theoretical framework:

> "There has to be an idea guiding what we choose to describe and how we choose to describe it. Ethnographers do not engage in what has been referred to lightheartedly as "immaculate perception." We do not and cannot simply *observe*, *watch* or *look*; we must observe, watch or look at *something*."

To conclude this section, there were four main reasons for choosing an ethnographic framework for this study. Firstly, ethnography is an interpretivist approach, being 'neither subjective nor objective' but rather 'mediating two worlds [audience and group studied] through a third [ethnographer]' (Agar, 1986:19), thus allows for both *etic* (outside observer) and *emic* (inside participant) perspectives to be captured. Secondly, the context value of this approach meant that children's perspectives of communication would be captured within the everyday natural context of the children's ward, thus creating a high degree of realism in which I would have limited control over events or behaviours (Savage, 2006; Hammersley and Atkinson, 2007 [1995]). Thirdly, the ability to be

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[74] There is no standard answer to: how many and what is a small number, it is a theoretical issue (Hammersley, 2008).
[75] At a later point, you will see my changing focus (section 4.5).
[76] One might use analytic categories 'further down the line' but not at the beginning (Hammersley, 2008).

flexible in the integration of a combination of data collection tools would facilitate a fluid, creative and developmental process of investigation (Mackenzie, 1994; Johnson, 1995). Fourthly, spending extensive time in the field would help to address such ethical and methodological considerations as the need to build rapport and trust with children and reduce the researchers' power status; whereby the researcher enters the world of the child as an active learner (Thomas and O'Kane, 1998). The next section will detail my experience of *doing ethnographic fieldwork* in a children's ward.

## SECTION C: DOING ETHNOGRAPHIC FIELDWORK

### 4.4. Doing Ethnographic Fieldwork

In this section, I detail the circle of interrelated activities involved in undertaking this ethnographic inquiry from the initial activity of developing the aim and objectives; locating the site; gaining access and ethical approval; recruiting and selecting a sample; collecting, recording, and analysing data. While I deal with each of these activities separately for ease of description, I recognise that ethnography is not a simple linear process but rather one that allows for flexibility with many directional changes as the research proceeds (Mackenzie, 1994). Issues in relation to undertaking research with children from an ethical perspective, and ensuring the robustness of the findings are also presented.

### 4.5. Developing an aim and objectives

Malinowski (1922) stipulated that one foundation stone for beginning ethnographic fieldwork is the possession of real scientific aims or foreshadowed problems; often first revealed to the observer through theoretical studies. This partly holds true for this study. For instance, at the outset of this study I discovered limited studies which explored children's views of their hospitalisation. Therefore, I began with the intention to explore children's perspectives of their hospital experience.[77] However, following a period of pilot work (Appendix 6) this broad focus became progressively narrower. I became

[77] Subsequent to this period in time, there have been a number of studies, which have directly explored children's views of hospitalisation as outlined in the background literature (see section 2.3).

interested in exploring children's experiences of communication with health professionals. Indeed, on return to theoretical studies I identified the extensive gap that existed in this area.

Such progressive narrowing is consistent with ethnography studies (Hammersley and Atkinson, 2007). Often the initial question is to ask, *what is going on here?* This equates to how I felt at the outset on the children's ward. I did not really know what I was looking for. It quickly became clear that I could not observe everything of what was going on 'there'. Children's hospitalisation was a huge area for exploration. As Wolcott (1999) contended to answer the question of, *what is going on here,* an additional related question in required, *in terms of what?* For example, in this study I moved on to ask, what is going on here for hospitalised children in terms of communication with health professionals? Wolcott (1999) highlighted that an ethnographic question should implicitly portray what it is the ethnographer is looking at and for and such questions should consider what one individual can accomplish in a limited timeframe. I had to consider what it was that I was explicitly looking at and for in terms of communication for hospitalised children. The following aim and objectives surfaced from drawing on communication theory and theoretical studies, in addition to my initial period of pilot work.

### 4.5.1. Aim

The aim of this ethnographic inquiry was to explore and describe the nature of communication between children[78] and health professionals, in a specialist children's hospital setting, from children's perspectives.

### 4.5.2. Objectives

1. To explore the process of communication taking place between health professionals and children in a child hospital setting; from children's perspectives.

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[78] For ease of reading children refers to children (6-11 years) and young people (12-16 years), unless otherwise stated.

2. To explore the role of the parent/guardian in the communication process taking place between health professionals and children in a child hospital setting; from children's perspectives.
3. To explore the role of the environment in the communication process taking place between health professionals and children in a child hospital setting; from children's perspectves.

The theoretical frameworks, the *circular transactional communication model* (Section 3.2.1) and principles of the *ecological model of human development* (Section 3.2.2), guided the development of these objectives. The transactional communication model links with the first objective, the *process* of communication that takes place between children and health professionals, who communicates with whom, what is communicated and how does this communication takes place. The next objective relates to the premise that because children are minors there would more than likely be a third party, their parent(s)/guardian, present. Thirdly, literature extensively outlines many environmental influences, which have an impact on the communication process. Here, environment refers to the immediate environmental context of the children's ward, but also broader social and cultural contexts, guided by the multi-system principles of the ecological model of human development.

### 4.6. Selection of Research Setting

Within ethnography, sampling is not only concerned with the selection of key informants/participants to give insight into the phenomena under study, but also with sampling across time and place (Mackenzie, 1994; Woodgate, 2000).[79] One thirty five bedded children's ward (which I call Barda Linbh[80]) within one specialised children's hospital (which the child participants entitled the KidZ hospital) was selected as the site for this study. I selected the KidZ hospital for ease of access. I chose Barda Linbh because it catered for a wide age range of children with diverse medical and surgical conditions. This ensured variations in children with different conditions, to characterise a

[79] Talking about the sample in terms of people and numbers dismisses context/environmental setting.
[80] Irish translation meaning children's ward

group of children experiencing the phenomenon (communication) under exploration. I only selected one children's hospital because selecting other hospitals might result in institutional differences and potentially change the direction of the study, with the risk of it becoming a comparative study between different cultural settings. A trade-off between breadth and depth was considered with the more settings studied the less time could be spent in each (Hammersley and Atkinson, 1995). In chapter 5, I will present the environmental scene and daily customs of the KidZ Hospital and Barda Linbh, the research setting for this study.

### 4.7. Gaining Access to the Research Setting and obtaining Ethical Approval

Gaining access and obtaining ethical approval to conduct research with children in hospital is often difficult (Stalker et al, 2004). One feature that differentiates research with children from adults is that prior to reaching child participants a hierarchy of adult gatekeepers must be surpassed (Hood, Kelley and Mayall, 1996; Coyne, 1998; Miller, 2000; Cree, Kay and Tisdall, 2002). Researchers should expect gatekeepers to test their motives, must be able to explain why children's participation is so important (Masson, 2004) and engage the trust and confidence of adults responsible for children's welfare (Thomas and O'Kane, 1998). For me, despite encountering many gatekeepers, namely, Ethics and Scientific Committees, Chief Executive Officer (CEO), Medical Board, Director of Nursing (DON), Clinical Nurse Managers (CNM), staff nurses, and parents, before meeting the children themselves, gaining access was relatively straightforward (although lengthy), possibly helped by my professional role in the healthcare arena (nurse identity). Ethical approval to conduct the study was sought from,[81] and granted by,[82] the University Ethics Committee, and the Children's Hospital Ethics and Scientific[83] Committee (Appendix 7[84]). I also negotiated access to the children's hospital with the

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[81] This entailed submitting appropriate application forms, covering study details, relevant ethical considerations and copies of parent/child information sheets and consent forms.

[82] I addressed all issues raised by Ethics Committees and approval was granted in writing to proceed.

[83] The Scientific Committee reviews research projects for methodological/scientific validity prior to the Hospital Ethics Committee. The application form was quantitatively organised, however all issues pertinent to this research study including ethical considerations were addressed. Along with copies of parent, and child, consent forms and information sheets, five referenced articles were included.

[84] I have hidden some aspects of letters to maintain confidential identity of place and persons.

CEO, DON and Medical Board. Appendix 8 details an overview of the process of gaining access and ethical approval to enter the research hospital site.

### 4.8. Establishing a Multidisciplinary Advisory Group

I established a multidisciplinary research advisory group to support and guide me in the conduction of this study; to ensure that the holistic needs of the children involved were met. The group comprised of two children (both with extensive experience of the hospital setting), a parent, child psychologist, play specialist, social worker, patient services manager and a representative from the voluntary organisation Children in Hospital Ireland.[85] A series of meetings took place before data collection began and over the course of the fieldwork when required. I maintained links with group members through emails, telephone conversations and personal meetings, to seek practical advice as needed. On completion of this thesis, advisory group members were contacted to arrange a meeting to feedback key findings, conclusions, and recommendations for practice, education, policy and further research. This verbal feedback will be supplemented with a written executive summary of the study.

### 4.9. Initial Entry into the Field: Preparing and Informing Health Professionals

In preparation for entering Barda Linbh it was deemed necessary to inform and prepare all hospital staff in various wards and departments about the study and my role as researcher (RCPCH, 2000[86]). I achieved this through the development and provision of information packs (made available on the children's ward) (Appendix 9) and by displaying posters in various departments (e.g. medical residence and department notice boards) to inform health professionals about the nature and intent of the study (Carnevale et al, 2008) (Appendix 10). The information packs were extremely important not only in informing health professionals themselves about the study, but also should parents ask health professionals questions or seek clarification regarding the study in my absence. I presented details of the study and my researcher role at a Clinical Nurse Manager

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[85] A paediatrician was invited to join but due to work commitments no one was able to attend.
[86] RCPCH (Royal College of Paediatrics and Child Health) formerly called the British Paediatric Association and originally published in 1992, revised in 2000.

meeting. I welcomed and was open to questions during informal liaisons with health professionals on Barda Linbh prior to commencing fieldwork. This provided me with different forums to present a brief outline of my study, discuss such issues as confidentiality, child protection, my role as researcher and address any questions or concerns. While health professionals did not actively participants in this study, they could have been part of observed encounters with children through their interactions with child patients.[87] Thus, I informed health professionals clearly that my intention was not to evaluate, criticise or intrude on their work, but instead to explore child patient's perspectives. I recorded health professionals anonymously (e.g. nurse, doctor) within my field notes. I reinforced information, verbally, through written information packs and posters displays at different points in time over the course of the fieldwork to capture staff rotations (Carnevale et al, 2008). Feedback from health professionals was positive with no major concerns raised.

### 4.10. Ethical Considerations

While most ethical issues that arise in work with adults (e.g. informed consent, confidentiality), also arise in work with children, there are important differences, which stem from children's diverse understanding, world experiences, ways of communicating and different power relations (Thomas and O'Kane, 1998; Punch, 2002a; Stalker et al, 2004). This section addresses ethical implications considered throughout this ethnographic research, namely children's right to full disclosure and self-determination; anonymity and confidentiality; and their right to not to be harmed (Murphy and Dingwall, 2001).

#### 4.10.1. Right to self-determination and full disclosure

A legal principle that regulates an individual's ability to agree to or refuse medical intrusion, informed consent, is also the principle that governs and controls participation in research (Lo Biondo-Wood and Haber, 1998). For valid consent, the person giving

[87] I was anxious about the inability to inform everyone who entered my line of vision when I engaged with child participants (see Murphy and Dingwall, 2001). I did endeavour to inform everyone (even retrospectively) who I was and what I was doing. Sometimes I had to make decisions about whether it was appropriate to include or exclude data from my field notes.

consent must have the capacity to understand and sufficient information to enable them to make the decision voluntarily without duress (Charles-Edwards and Casey, 1992; Department of Health UK, 2001a&b; Beauchamp and Childress, 2001). Historically, adult proxies (parents and health professionals) were accredited authority for making decisions about children's medical treatment or participation in research (Mahon et al, 1996). This was partly a consequence of children's professed legal, vulnerable and developmentally incompetent status (Committee on Bioethics, 1995).[88] Children are often believed to be incompetent by virtue of their age and juvenile group membership based on their vulnerability, limited social power, reduced cognitive ability and limited experience (Alderson and Morrow, 2004; Dolores and McCarthy, 2005). Arguably failure to consult with children results in an escalation of their powerlessness and social exclusion; with proxy consent prohibiting the execution of the principle of self-determination (Allmark, 2002). Recent social and political changes have recognised children's right to self-determination, encouraging the expression of their opinions and participation in decisions that affect them (UNCRC, 1989; Department of Health and Children, 2000). However, prior to embarking on obtaining children's consent it was necessary to engage with many guidelines and theoretical papers.

Despite extensive discussion in the literature,[89] there remains much ambiguity about children's consent to research with many unanswered questions (Alderson, 1995; 2005), within which the law has not been clearly delineated (RCPCH, 2000). The majority of debates on children's consent to medical interventions and research participation centre on the age at which children are competent to consent. However, there appears to be no age consensus as to when children are competent.[90] Others argue for less prescriptive age

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[88] It is interesting to note, as Farrell (2005) remarked, the different perspectives on children's ability to consent to research are embedded within our understandings of children and childhood. For instance, if children are viewed as *becoming* proxy parental consent is sought; if children are viewed as *being* children's consent is sought; whereas if we consider children as both *being* and *becoming* (and I am of this perspective) then both parental consent/permission and children's assent/consent is sought.

[89] National Children's Bureau (1993); Alderson (1995; 2000); Allmark (2002); Perex-Corceles, Osuna, and Luna (2002); Diekema (2003); Masson (2004); Alderson and Morrow (2004); Kodish (2005); Alderson (2005); Neill (2005); Cocks (2006); Bray (2007b); Ford, Sankey and Crisp (2007).

[90] For example, in relation to medical intervention, children 16 years and over are seen capable of giving valid consent to surgery, medicine and dental treatment (Office of Public Sector Information, 1969; Office

demarcations, proposing a developmental, individualised, and context specific evaluation of children's ability to consent (Alderson, 1993; 1995; 2000; 2005; Perex-Corceles, Osuna and Luna, 2002; Kanner, Langerman and Grey, 2004; Kodish, 2005). Ultimately, it is the role of the researcher to inform, evaluate (understanding and competence) and assist children to make a wise decision without exerting pressure (Lowes, 1996; Hill, 1998; Alderson, 2004).

A more transparent agreement exists upon the necessity to obtain parental consent, prior to involving children (RCPCH, 2000; Department of Health UK, 2001a&b). The National Children's Bureau (1993) highlighted an important factor that children give ultimate consent to participation, whereas parents give consent for the researcher to invite their child to participate. Illustrating a triangular relationship between parent, child and researcher, Kodish (2005) asserted that within paediatric research informed consent involves the process of parent permission in addition to child assent. This is akin with Subpart D of the American Code of Federal Regulations outlining protection for child research subjects (Nelson, 2003; Code of Federal Regulations, 2004 updated) and Paragraph 25 of the Helsinki Declaration (World Medical Association, 2000 updated). It was these aforementioned principles that guided me in this study. I respected children's capacity to assert their own wish to participate, or not. I also recognised parents' responsibility and role. By using Kodish's triangular (child-parent-researcher) partnership I acknowledged parental responsibility and respected children's autonomy, alongside safeguarding their welfare (Appendix 11).

Lindeke, Hauck and Tanner (2000) defined assent as *affirmation* to participate in research. Assent recognises that where children are not able to legally give valid consent

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of the Attorney General, 1997; Alderson, 2000; McHale 2001). For children less than 16 years, the House of Lords in the UK asserted that children might be competent to give legally effective consent, independent of their parents, provided they had sufficient understanding and intelligence to comprehend fully the nature and consequences of medical intervention (Van Dokkum, 2005). In relation to research, Wendler and Shah (2003) fixed the age of assent at 14 years, whereas Kanner, Langerman and Grey (2004) suggested 7 years and over. Ondrusek et al (1998) believed that one could not expect children less than 9 years to consent or assent to clinical research in a meaningful way. Weithom and Campbell (1982) also contended that children aged 9 years were able to make decisions, whereas Hill (1998) maintained that children as young as 3-4 years can have some understanding.

for themselves, it is important to involve them as much as possible in the decision about whether they would like to participate in non-therapeutic research (Department of Health UK, 2001a&b; Hallstrom and Elander, 2004; Ford, Sankey and Crisp, 2007). Diekema (2003:26) outlined what this assent process involves: "assent is interactive instructional process that includes the investigator, the parents and the child with the goal of assuring that the child has at least a simple understanding of the study purpose, the procedures that will directly involve the child, and the possible harms and benefits of participation".[91] Thus, for assent to be valid; it must to be appropriately informed; children must have a reasonable degree of understanding about what to expect; and comprehension of their ability to refuse to participate. Prior to asserting written assent, I provided detailed verbal and written information to both parents and children.

#### **4.10.1.1.** *Informing parents*

On visiting the children's ward daily I liaised with clinical nurse managers and staff nurses to assess children's health status and capability to take part. Following identification of potentially suitable child participants I undertook a ward round to invite children to take part, firstly approaching parents.[92] I personally approached parents to provide them with information about the research. While the prospect of having an independent gatekeeper to approach parents/children (in terms of omitting any risk of coercion) was considered at the outset of the study, in reality owing to the context of the children's ward, in terms of the high child patient turnover, the ad hoc coming and going of parents and the business of health professionals, on reflection this was not a viable option. Also, I did not want parents/children to perceive that this study would in some way influence the care they received in the hospital. However, in an attempt to address this, information leaflets and posters were displayed on the ward to initially alert parents and children to the fact that this study was taking place on the children's ward (Appendix

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[91] Some recent valuable resources that might assist with this process are Danby and Farrell's (2005) examples of children's competence as they engaged with children in research conversation openings.

[92] Sometimes when I approached parents, their children were in the nearby vicinity perhaps eavesdropping in the background. Interestingly, this mirrored aspects of the findings of this study which I will report on later. This highlights that parents were gatekeepers through which to negotiate access to their children for the purposes of this research, but also for health professionals in terms of communicating with their children, as will be evident at a later stage.

12). If parents expressed interest in hearing more about the study then I arranged to meet with them to verbally discuss the study in more detail and provided them with more extensive written information. Initially I verbally discussed what the research involved and followed this with a written information sheet (Appendix 13). This form outlined the purpose/nature of the study, risks and benefits, confidentiality, privacy and child protection issues. I informed parents that they could be present with their children at all times. Parents were encouraged to ask questions and I answered any queries they had. Some parents questioned me further about the research and one parent asked whether it mattered if children knew or understood what was going on. This surprised me somewhat at the time ('I was a bit taken back') but reflecting back and considering this statement in light of the dichotomous nature of findings of this study, in relation to communicating with children, such questions would not be so unexpected (as will be seen later). As mentioned above, while some might deem it coercive (i.e. be difficult for parents to dissent) for me, the researcher, to have approached parents personally, I made it explicitly clear to parents that they did not have to grant permission for me to approach their child to invite him/her to take part in the study. I also reflected on, and kept field notes of my interactions with parents, through which I became increasingly aware of and sensitive to subtle signs of refusal and/or hesitant agreement (see Section 4.10.1.4).

#### **4.10.1.2.** *Parent consent/permission*

To safeguard the welfare of children and respect the role of parents', I sought parental written consent to grant me permission to approach their child for participation in the study. The majority of parents approached gave permission for me to invite their child to participate. I initially discussed the study and my role as researcher on the children's ward with parents. My conversations with parents often turned into a mini forum for parents to ventilate their concerns and issues about the hospital. If parents thought their child might be interested in taking part then I provided detailed written information for both the parent and their child to read at their convenience (as outlined in sections above and below). I either returned some hours later on the same day or the next day to establish their interest and willingness for me to approach their child to invite him/her to

participate, or not. If so, then I obtained written consent from parents for me to do so (Appendix 14).

I faced challenges in relation to recruiting children because of difficulties with accessing parents. Parents were not always present at times when I was present. It was sometimes difficult to catch up with parents depending on the times they visited. Then often there were also other family members or visitors with them and it felt awkward to interrupt; or they wanted to speak with doctors. I was conscious of this at the outset because with the child patient turnover I really wanted to approach them early so that I could spend as much time as possible observing and interacting with the same children. This was not always feasible. Parental consent was a once off process as opposed to child assent, which was an ongoing re-negotiated process, as will be outlined below.

#### **4.10.1.3.** *Informing children*

Once parents consented (in writing) for me to approach and invite their child to take part, I approached the children to inform them about the study and invite them to participate. Firstly, I discussed the study and children's role verbally with them using clear and simple language meaningful to children (e.g. words such as project, conversation and not research and interview) (Mauthner, 1997). Parents were present at this time and proved invaluable in assisting with younger children's language and understanding. Following, and often alongside, my verbal explanation I provided children with written information. At the outset of the study, I designed information leaflets specifically for children. I took great care in devising these forms in a child friendly and developmentally appropriate manner; using simple language, large print and incorporating diagrams and pictures (Alderson, 1995; 2005). Using colourful clipart and a question answer format, these forms outlined the purpose and nature of the study, procedure, risks and benefits, confidentiality, privacy, the option to withdraw, child protection issues and my contact details (RCPCH, 2000; Department of Health UK, 2001a&b). I devised two versions, one for younger (Appendix 15) and one for older children (Appendix 16). Two children from the advisory group assisted me with reviewing drafts of these information sheets, which I

modified to incorporate their feedback.[93] These leaflets were deemed valuable as an extra written resource to add to the verbal explanation I gave to children on 'who, what, why and how' about the project.

Sometimes I read the written information aloud to children (Ford, Sankey and Crisp, 2007). Other times, children wished to read the information leaflets. In some cases, children would ask me words they did not understand or other questions about the project. For children, who did not, I asked them to circle or point out words if they did not understand them. I would then substitute words appropriate to the child's level of understanding. Some things children commented on when reading the information sheets were; the importance of the statement there are no right or wrong answers; does the drawing have to be good; and some were amused about having a pretend name. I provided children with an opportunity to ask questions and addressed any concerns (Olechnowicz et al, 2002). This aimed to avoid a one-way researcher-centred process of information transmission (Bridson et al, 2003; O'Neill, 2003; Bray, 2007b).

A two-way process was deemed invaluable as a way of determining children's understanding, or lack of, of who I was and what I was trying to do; often manifested in their questions and expressions of concern (Brook, 2000; Bray, 2007b). For example, after explaining to Maria (10 years) about the project, and who I was, she asked; *are you a doctor?* I felt slightly deflated. What I learned from this example was that information provision has to be an individualised process, is influenced by context (by the pure fact that I was based in hospital Maria presumed I was a doctor) and should not be a one off endeavour. Once I explained again to Maria who I was (a student in college) and about the project, Maria asked me where the college was, was it far and did I drive. This was often the case; children were particularly interested firstly in finding out about me before further discussion about the project. Therefore, information was relayed on a daily basis to child participants about who I was and what I was doing. Over the course of spending time with the children they asked me more questions and were able to absorb more

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[93] Recently, Ford, Sankey and Crisp (2007) reported how they involved children (6-12 years) in the development of the information and assent forms. Another recent valuable resource is Farrell (2005).

information. One challenge was to collaborate an appropriate time amid hospital routines and activities (play station, game boy, TV, playroom, school) to talk to children. As mentioned previously (Section 4.10.1), in addition to adequate information and understanding about what to expect in the research children must also comprehend their ability to refuse to participate (dissent).

**4.10.1.4.** *Children's voluntary assent*

Voluntary participation is a basic ethical requirement of participation in research (Ondrusek et al, 1998; Bray, 2007b). It entails freedom to choose and decide without coercion from others. All healthcare research has potential *voluntary* difficulties due to the power divide that exists between health professionals and patients (Allmark, 2002; Bray, 2007b). The risk is that patients (children and their parents in the context of this study) feel compelled to take part out of apprehension, appreciation or belief that they will receive better care. Children, and their parents, are in a vulnerable position in hospital (which tips the balance of power) and it could be difficult for them to decline to participate (Hallstrom and Elander, 2004). The age difference between the adult researcher and child participant further exacerbates the power divide. Children may agree to take part merely to please, and/or because they have learnt to respect and obey adults (Jolley, 1995; Lowes, 1996; Kortesluoma, Hentinen and Nikkonen, 2003; Bray, 2007b). Ondrusek et al (1998) found that, regardless of age, children's belief that the researcher would be unhappy if they withdrew from the research possibly prevented children from withdrawing from the study. This highlights the importance for researchers to ensure that children are aware that they [researcher] will not be upset if they withdraw.

I was very mindful of these propositions and suggestions throughout my study. I obtained written assent from all children interested in taking part. Similar to the information sheets I designed assent (O.K.) forms specifically for children and young people; using simple terminology and pictures as appropriate (children from the advisory group also reviewed these assent forms) (Appendix 17 and 18). However, I viewed children's assent as an

ongoing process and not a mere one off event[94] (Alderson, 2005; Carnevale et al, 2008). Thus, in addition to written assent at the outset, verbal assent was renegotiated on a daily, or more frequent, basis at various times of informal conversations and participant observations.[95] It was made explicitly clear to children (both verbally and in writing) that their participation was voluntary; it was up to them to decide whether to take part or not; they had the right to refuse (say no) and withdraw (change their mind) at any time, without penalty, and they did not have to say why. I also tried to ensure that parents and children were not agreeing with the belief that they would receive better care. I also stressed that it was important that children did not feel obliged to take part because of perceived parental expectation to do so. It was clearly delineated at the start of the study that if a child (whatever age) refused to take part, or wished to withdraw at any time, data collection with that child would be stopped, even if there was continuing parental consent (Department of Health UK, 2001a&b).

Two children refused to take part. One child did not give a reason and the second child stated she did not want to chat. Their refusal was respected and, similar to Cocks (2006), while I was perhaps initially disappointed at their refusal (from a data collection perspective), I was content that children's ability to refuse and stop demonstrated genuine voluntary assent. In a few cases, whereby children had agreed to participate, I reflected upon whether they really did *voluntarily* assent. This was because when I spoke with these children, following their affirmed assent, they contributed minimally to the interaction. While children may be non-communicative for a number of reasons (e.g. unfamiliarity with researcher, lack of interest in the topic of discussion), one key reason to consider is the possibility of children's reluctance to take part. I took some solace in the contention that although children might have involuntarily agreed to take part (e.g. afraid to refuse), they could still exert their own power in deciding what to disclose (share or withhold) within our interactions (Neill, 2005; Danby and Farrell, 2005).

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[94] This is essential in ethnography as consent is not a one off event but an ongoing negotiated process.

[95] Moore and Savage (2002) identified the difficulty of establishing firm boundaries around the research field. I found it difficult to avoid observing non-consenting children who were marginal to the boundaries of my observations. I addressed this by ensuring everyone (staff, children and parents) knew about the study. I introduced myself daily and only included consenting children in my written field notes.

An issue I became aware and conscious of, when approaching parents and children, was subtle or covert signs of refusal (Diekema, 2006).[96] For instance, parents may not have refused outright for me to approach their child, nor did they give their permission either. Some examples of subtle signs of refusal were, '*he is tired*', '*she is not feeling well*', '*he is going to playroom now*' or '*we might be going home later*'. There were also examples of these subtle signs of refusal after parents had agreed for their children to participate, thus illustrating the necessity for ongoing re-negotiation (Appendix 20). Similar to parents, some children did not overtly agree or refuse to take part, but rather stated things like, '*not today tomorrow*' or '*I think I'm going home later*' or '*not today I'm tired*'. On the other hand, there were children who told me that they did not want to take part, play or chat, or wanted to stop and take a break at different times throughout my fieldwork. This was especially if they had peer and family visitors, or if they wanted to play games or watch their favourite TV programmes. A more convenient time to return to these children was re-negotiated, if they so wished. Thus, it was important to be alert for not only children's initial but also their ongoing responses (Cocks, 2006). My previous nursing experience and observation skills assisted me in being aware of when children appeared tired or grimaced in pain. At such times, I directly asked children were they tired or in pain and if so stopped the research to allow them to rest, get appropriate pain relief and returned at a later stage, negotiating assent again. Also similar to Cocks (2006), some children demonstrated their ongoing assent to my presence through their actions, for example asking staff nurses of my whereabouts and personally approaching me to engage in their games or to assist me further with the project.[97]

### **4.10.2.** Right not to be harmed

The overriding concern of those involved in research is to ensure that participants come to no harm (Wagstaff and Gould, 1998). Non-maleficience and beneficience are core principles correlated with the *right not to be harmed*. In this study, the welfare of children and their family was always the first consideration outweighing any commitment to the

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[96] See Bray (2007b) for similar concerns over issues relating to voluntary-ness.
[97] I would agree with Cocks (2006) in her contention that assent is represented by the trust and acceptance of the researchers presence within the researched-researcher relationship.

research. Non-therapeutic research that confers no direct benefit should impose only minimal risk (i.e. not greater than experienced in everyday life) (Allmark, 2002; Carnevale et al, 2008). As this research study was non-therapeutic in nature, it was clearly outlined both verbally and in writing that there were no direct benefits to child participants and their family, although other hospitalised children might benefit in the future. This ensured that children and their families clearly knew what they could and could not expect.

Through participation in this research, children were involved in a decision-making process and given an opportunity to express their views. Furthermore, it was hoped to foster a better understanding of the processes of communication that take place between children and health professionals, from children's perspectives. While it was difficult to estimate at the beginning what harm might occur from questioning and interviewing procedures it was acknowledged children could get upset especially if questions triggered memories of distressing experiences or feelings (Murphy and Dingwall, 2001). I set out a protocol of what to do should this happen, which entailed that I would provide immediate support, be respectful and stop the research. I would recognise the limits of my expertise and resist giving advice beyond my area of competence but rather seek the assistance of colleagues (e.g. multidisciplinary advisory group). None of the children became distressed while conversing about their experiences. Drawing on the work of Hill (1998), Masson (2004), Alderson (2005) and the School of Psychology, Trinity College Dublin (2006 [2003]) the following steps were also undertaken. I had previously obtained Garda Clearance for any criminal offences against children, having worked as a RCN prior to undertaking this research study. I signed a statutory declaration stating that I had no previous criminal record of offences against children and submitted this to the Director of Research, School of Nursing and Midwifery Trinity College (Appendix 19). By employing an ethnographic approach this research took place in the open visible ward environment, thus avoided any unsupervised contact with children in an unfamiliar formal setting.

**4.10.3.** Right to anonymity and confidentiality

I will address two issues here, *protecting children's identity* and the *guarantee of absolute confidentiality.* First, I protected children's identity by ensuring all data was devoid of any identifying features. All data (hand written and word documents) from fieldwork, field notes, drawings and stick-a-star quiz, did not have any real names recorded on them and they were stored locked in a secure place with access available only to me. I restricted access to all data transcribed to my personal computer, for storage and analysis, by passwords (known only to me). No data was unattended during fieldwork. It was with me at all times or locked in a secure place, accessible only to me. I locked names, addresses and demographic details of child participants in a separate press away from the collected data. I took similar steps to disguise the identity of the child participants throughout this thesis, conference presentations and publications, by assigning pseudonyms to child participants. I disguised anything contained within the data and text that might expose or lead to tracing of child, family or place.

While in ethnographies it is usual to name the research setting this was not possible here in order to maintain child participant anonymity and confidentiality (as stipulated within my ethics applications and my assurance to child participants that their identity would remain secret). The fact that this study took place within the real live context of one children's ward health professionals in this setting were aware of who the child participants were (Murphy and Dingwall, 2001). When negotiating access and during information sessions held with health professionals at the start of my fieldwork I stressed the necessary to respect children's confidentiality. The University Faculty Ethics Committee suggested that parents be present throughout the data collection period.[98] My experience within the field was that sometimes parents were present, when I observed and interacted with their children, and at other times, they opted not to be present (often using the opportunity to have a break while I was there with their child). Thus, I

[98] This stipulation was on my original ethical application where I had stated I would be conducting formal structured interviews with children off the open ward. I did not undertake any formal structured interviews alone with children, I was always on the open ward with children, and thus I did not have any unsupervised contact with the children.

discussed the option of parental presence with both parents and children at the time of sharing information and obtaining consent.

Two different view points can be taken on parental presence during data collection, both of which I experienced during fieldwork. One side of the coin is the risk that parents may constrain children's participation and hinder children's privacy and confidentiality. This did not happen often, but on occasions parents 'butted in' to answer on behalf of their child. In light of some of the findings reported in this thesis (as will be evident later) this was perhaps not surprising. In an attempt to address this, when parents were present, I stressed that I was interested in their child's view. I felt awkward and uncomfortable on these occasions. On the other hand, parents often assisted with communication and trust between their child and me (Appendix 20).

The second main issue arising under confidentiality was the limit of guaranteeing absolute confidentiality.[99] I made it explicitly clear at the outset of the study that should I witness any unsafe practice or procedure detrimental to the safety and well-being of any child that I would be obliged under my Code of Professional Conduct to safeguard the welfare of the child (An Bord Altranais, 2000). I clarified that if any child disclosed information to me that she/he or anyone else was at risk that I would be obliged under the Children First: National Guidelines for the Protection and Welfare of Children to safeguard the welfare of the child, regardless of the effect this would have on the study (Department of Health and Children, 1999). I explained that if it became necessary to breach confidentiality I would discuss this with the child and family. I developed a clear protocol to guide me should this happen. No such dilemmas emerged within the study.

While I sought guidance from numerous documents,[100] I was mindful that sound ethical conduct in research goes beyond written guidelines to draw on the researchers' integrity

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[99] Refer to National Children's Bureau (1993); Hill, Laybourn and Borland (1996); Mahon et al (1996); Kendrick and Taylor (2000); Balen et al (2000/2001); Allmark (2002); Alderson (2004)

[100] World Medical Association (1964/2000); British Paediatric Association (1992); National Children's Bureau (1993); RCPCH (2000), UK Department of Health (2001a); National Association for People with

(Cree, Kay and Tisdall, 2002; Alderson, 2005). While I attempted to think-through ethical issues that could arise prior to embarking upon this study (and developed protocols and addressed these thoroughly in my ethical applications) (Greig and Taylor, 1999) I was also aware that:

> "A paragraph or two about ethics is quickly written and added rather as decoration like a cherry on a cake. Ethics are however far more useful when they are seen as a vital part of the whole recipe" (Alderson, 2004:110).

This was particularly important within the context of this study, which took place openly on a children's ward with sick children as participants. It was important to use my discretion on an ongoing basis about when and where it was appropriate, or inappropriate, for me to be present.[101]

### 4.11. Selecting Child Participants

I purposively selected child participants[102] from child patients admitted to Barda Linbh at the time of data collection. In ethnography participants are purposively or judgmentally selected based on their role, knowledge, insight, willingness and ability to discuss their experience (Baillie, 1995; Fetterman, 1998; Roper and Shapira, 2000; Hammersley and Atkinson, 2007 [1995]). In this study child participants tended to be children whom I would be able to have most contact with, therefore build stronger rapport with, and those who spoke more freely. The following inclusion criteria guided the selection of child participants; (a) admitted to the selected children's ward at the time of data collection; (b) admitted for an overnight stay; (c) aged between 6 and 16 years; (d) able (medically stable) and willing to take part; and (e) had parental consent.

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an Intellectual Disability (2003); School of Psychology Trinity College Dublin (2003); UK Royal College of Nursing (2004)

[101] An example of this is provided in a sensitive extract from my observational fieldnotes on page 193 and reflection in footnote 186.

[102] I have chosen to use the term participants because of the negative connotations of betrayal attached to 'informants' (Boyle, 1994; Carspecken, 1996; Roper and Shapira, 2000).

Defining the specific characteristics (e.g. age, specific condition/illness) of the child participants posed some challenges.[103] Arguably, the greater the similarity in child ages and cases would enhance consistency/dependability. However, I believed that being too narrow and prescriptive would fail to represent the diversity of child patients that were cared for together on Barda Linbh. Barda Linbh admits children of all different ages, with a variety of both medical and surgical problems, and with both acute and chronic conditions. I deliberately selected a diverse age range and children with a variety of both medical and surgical conditions to reflect the holistic category of patients admitted to Barda Linbh. I felt this was important to ensure that child participants selected in some way portrayed the real natural context of the children's ward where fieldwork took place. While the KidZ hospital usually admits children only up to the age of fourteen years, I selected the upper age range of sixteen years to take account for the fact that some children on reaching their fourteenth birthday, who already receive care at the KidZ hospital often continue their treatment to completion there. One child participant had autistic mannerisms associated with a syndrome (which I do not explicitly refer to within this thesis to ensure anonymity). Children deemed too ill to participate were excluded, however once improved and deemed able and willing to participate they were invited to do so.

### **4.11.1.** Profile of child participants

In total, forty-nine (49) children participated. The availability and accessibility of parents and children, in addition to admission rates and patient turnover, within the timeframe of the fieldwork, determined the sample size. Background characteristics of the child participants collated are summarised in Table 1 (see Appendix 21 for more extensive details).

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[103] Numerous debates in relation to this diversity of sampling took place at PhD support groups meeting. I acknowledge that this sample is not homogeneous and encapsulates a wide age range of children. However, firstly, it is somewhat representative of the range of children who attended the children's ward and secondly even if all children were of a similar age, homogeneity still would not exist for there are many different childhoods. Thus, we must not assume an age dominated perspective on childhood (James, Jenks and Prout, 1998; Emond, 2005).

**Table 1: Background Characteristics of Child Participants *(n=49)***

| Characteristic | Number of participants |
|---|---|
| **Age Range** | |
| 6-11years | 29 |
| 12-16years | 20 |
| **Gender** | |
| Boys | 22 |
| Girls | 27 |
| **Mode of Admission** | |
| Emergency | 31 |
| Elective | 13 |
| Out-patients | 4 |
| Inter-hospital transfer | 1 |
| **Reason for Admission** | |
| Medical problem | 15 |
| Surgical problem[104] | 34 |
| **Length of Hospital Stay** | |
| < 7 days | 40 |
| < 14 days | 5 |
| 20-30 days | 4 |
| **Previous Hospitalisation** | |
| Yes[105] | 30 |
| No | 19 |
| **School** | |
| Primary | 33 |
| Secondary | 13 |
| Unknown | 3 |

### 4.12. Gathering and Producing Data

To empower and obtain child led data it was imperative that I choose age appropriate child-led methods (Prout, 2000; Balen et al, 2000/2001; Punch, 2002a&b).[106]

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[104] The majority of children selected had surgical problems as opposed to medical. Some potential reasons for this are that there was slightly more space for me to manoeuvre on the surgical end of the ward and children with medical problems tended to be sicker and younger (under 5 years).

[105] Refer to Appendix 22 for more specific details on children's previous hospitalisations.

[106] For examples of a variety of methods refer to, Hanna, Jacobs and Guthrie (1995), Herth (1998), Polkki, Pietila and Rissanen (1999), Noyes (2000), Nesbit (2000), Sartain, Clarke and Heyman (2000), Wesslen,

Incorporating a range of specific activities into an interview appears to be a workable alternative to a rigid question and answer format, making the interview more stimulating, varied, fun and interesting (Mauthner, 1997; Punch, 2002a&b; Coad, 2006; 2007). Furthermore, it enhances children's cooperation, acts as a springboard for discussion, recognises children's diverse abilities and preferences and helps lessen the unequal adult researcher – child participant relationship (Mauthner, 1997; Balen et al, 2000/2001; Punch, 2002a&b; Coad, 2007).

Within this study, I generated data through fieldwork, which incorporated semi-participant observations, informal conversations, participatory activities (draw and write technique and stick-a-star quiz) and documentary evidence (e.g. policies, philosophies, written information for children/families).[107] Fieldwork spanned over four months from October 2004 to February 2005. I visited Barda Linbh for a total of fifty-three (53) days spending anything from three to five days per week there, with all seven days represented over the course of my fieldwork.[108] In total, I spent two hundred and forty five (245) hours on Barda Linbh. Daily, I spent anything from one to eight hours on Barda Linbh. Throughout the duration of the fieldwork, the time periods covered ranged from 07.30 to 19.00 hours (Appendix 23). This ensured that I captured a comprehensive picture of typical everyday activities and occurrences on the children's ward (somewhat representative of different times of days and days of week). For clarity, I describe the multi-methods employed separately in a linear fashion as if they were distinct and took place sequentially. However, in reality, they overlapped and all interlinked to form a matrix. The sequence in which I employed them was not prescriptive and often occurred simultaneously. As Fetterman (1998:2/9) highlighted:

> "Ethnographic work is not always orderly. It involves serendipity, creativity, being in the right place at the right or wrong time, much hard work, and old fashioned luck.....The most important element of fieldwork is being there - to observe, to ask seemingly stupid insightful questions, and to write down what is seen and heard."

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Sepp and Fjellstrom (2002), Carney et al (2003), Darbyshire, MacDougall and Schiller (2005). Also see, Coad and Lewis (2004), McCabe and Horsley (2008) and Coad (2007).

[107] This is consistent with ethnography where multiple data collection methods are used, principally observations and interviews (Baillie, 1995; Laugharne, 1995; Hammersley and Atkinson, 2007 [1995]).

[108] This intensity contrasts with other studies where visitations are spaced out over months and years.

### **4.12.1.** Participant observations

Observations allow access to events as they happen. They are a valuable tool for discovering human behaviours, routines and interactions within specific contexts of everyday life (Darling and Scott, 2002).[109] Within ethnography, observations are a fundamental mode of data collection with the researcher being the prime instrument of data collection (Baillie, 1995; Hammersley and Atkinson, 2007 [1995]). Spradley (1980:39) stated that "wherever the ethnographer may go and whatever the size of the social unit (a street corner, a village, a town, a city), all participant observation takes place in *social situations*". In turn, each social situation comprises of three key elements; actors (particular kinds of people), activities and place (any place as long as it has people present and they are engaged in activities). In undertaking participant observations, I located myself in Barda Linbh, observed and participated with children in different activities, interacted with them, and questioned them about interactions and activities with health professionals (Spradley, 1980). While I did not have any pre-set categories of what to observe,[110] I was guided by Spradley (1980) and Merriam's (1998) broad suggestions on what to observe (Appendix 24). Although, these suggestions appear to be clearly delineated, I often still felt initial confusion about what I should and should not be observing and what I should be recording, especially in terms of how much or how little. Initially, my observations remained at a broad descriptive level whereby I attempted to record as much as possible of everything and anything in the scenes I encountered. However, over time, after recording and reviewing field notes on an ongoing basis I became more selective and focused in what I was observing and thus in what I needed to record. To assist with focusing I often referred back to my research objectives and guiding theoretical frameworks. Also, data analysis began at this point of collecting and recording data as I continually made choices about what to observe, which data to remember, write down and in what way (Johnson, 1997). However, I was mindful not to move to quickly to an interpretive level before firstly adequately describing the concrete

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[109] Unlike interviews, observations present access to events as they happen. Parahoo (1997) contended that in practice-based professions, such as nursing, observations, whether used in isolation or in conjunction with other tools, are probably one of the most beneficial means of collecting data.

[110] Tudge and Hogan (2005) caution us to be mindful of the fact that preset categories of observations might not resemble children's experiences and thus exclude them.

particularities of actions and behaviours taking place in the field (children's ward) (Emerson, Fritz and Shaw, 1995; Hammersley and Atkinson, 2007). Thus, I distinguished analytical thoughts from descriptive field notes by using double round brackets. Some challenges encountered during my observations were space, or lack of it, which often determined what I could and could not observe. The vast array of activities going on around me also affected observations. For instance, I often could not observe behaviours or interactions happening simultaneously, or those outside my line of vision. If I was too far away I could not clearly hear the spoken word, especially within the context of the busy noisy real-life clinical environment. See Appendix 25 for sample extract from observational field notes.

#### **4.12.1.1.** *Deciding on a participant observation role*

As researcher, it is vital to decide on an observation role to assume. Gold's (1958) frequently cited typology outlines four different observer roles; complete participant; complete observer; participant as observer; and observer as participant.[111] Others view observation and participation along a continuum contending, firstly that the observer is always in some way a participant, their presence always having some influence on the setting (Darling and Scott, 2002). Secondly, the role of the ethnographer ranges from complete observer to complete participant and may change throughout the course of the fieldwork (Hammersley and Atkinson, 1995). However, it was also important for me to consider my epistemological assumptions about children as social members because this would ultimately influence the role I adopted (Mandell, 1988; Harden et al, 2000; Robinson and Kellert, 2004). In relation to adults undertaking research with children, the type of role adopted by the adult plays an important element in the power relation dynamics (Kellert and Ding, 2004). Mandell (1988) outlined three membership roles

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[111] Complete observer: researcher has no contact with people he/she is observing, observe through one-way mirror. Complete participant: researcher is member of group studied but conceals his/her observer role. Observer as participant: researcher takes no part in activities but participants know of their research role. Participant as observer: researcher known as observer to participants; establishes relationship and participates in activities with them asking them to explain what is going on (Gold, 1958).

often adapted by researchers when studying small (preschool) children. These are detached observer, semi-participatory role and complete involvement.[112]

Considering these roles, if we view *children as completely different to adults* we would assume a detached observer role and research children from an impersonal objectivist stance. On the other hand, if we consider *children to be the same as adults* then we would adopt, as Mandell did, a complete involvement role casting aside our adult superiority (apart from our larger physical size) and enter the child's world as a fully active participating member. Others disagree and contend that it is never possible for adults (size, age, authority) to remain unnoticed in the presence of children (Fine and Sandstorm, 1988; Christenson, 2004). Indeed, Mandell (1988) highlighted a number of disrupted engagements with children acknowledging that as an active participant she made mistakes by acting in non-childlike ways. Perhaps, by adopting a 'child-like' position the adult tries to dispel his/her powerful role/position over children.

I found both these two roles of *detached observer* and *complete involvement* hard to conceptualise because as an adult, I did not see myself as completely superior to children, but I did not see myself as equal to them either. I was older and perhaps had more knowledge in relation to healthcare and the hospital environment. However, I was not more knowledgeable about the *play-station* or *game-boy*. This is perhaps not surprising considering I grew up in a different era where such technologies were not so easily accessible. Indeed, despite training as a children's nurse and caring for hospitalised children, I felt I lacked knowledge of children's perspective of hospitalisation, healthcare and hospital environment.[113]

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[112] Looking closely at Mandell's (1988) three membership roles similarities with the sociological debates of how we view children is evident. That is do we see children as being (complete involvement), becoming (detached observer) or both being and becoming (semi-participatory role).

[113] Some adults would argue that having once being a child themselves enabled them to know the child's perspective, I did not uphold this view. Indeed, my childhood was probably very different from other adults from a similar childhood era to mine. Furthermore, experiences are continuously changing. This was important because as Robinson and Kellert (2004) contended if adults believe they hold superior knowledge to children the unequal adult-child power divide is sustained. This provides an obstacle for engaging in participatory techniques and research with children.

Furthermore, Emond (2005) contended that it may be problematic to undertake ethnographic research with children from either extreme of a complete observer or complete participant continuum. A complete participant role with children would be open to suspicion and a wholly observation role could be upsetting to the children. Thus, I adopted a semi-participatory observer role (James, 2001; Emond, 2005)[114] within which I viewed *children as similar to adults but with different competencies* (Punch, 1998). This semi-participant role meant assuming a friendly non-authoritative marginal role. The goal of this role was not to adopt an equal peer status with children but rather to recognise and minimise differences (such as age, cognitive development and physical maturity) by taking on a less threatening role of "non-interfering companion" (Mandell, 1988). This semi-participant role acknowledges that there are limitations to the extent to which the researcher can participate in children's activities. Punch (2002a:338) highlighted the need for flexibility in the role adopted:

> "It is too simplistic to consider research with children as one of two extremes: either the same or different from adults. Instead it should be seen as on a continuum where the way that research with children is perceived moves back and forth along the continuum according to a variety of factors: individual children, the questions asked, the research context, whether they are younger or older children and the researcher's own attitudes and behaviour. Researchers need to be flexible throughout the research process."

#### **4.12.1.2**. *My field role as semi-participant observer*

My semi-participant role involved spending prolonged time (varying times and shifts) daily in Barda Linbh, to immerse myself in the day-to-day life of children in hospital, and to capture daily experiences and interactions between children and health professionals. This enabled me to build rapport, engage in activities with and listen to children's perspectives, in addition to maintaining a degree of marginality avoiding over-rapport, disrupting natural states and hindering objective outcomes (Hammersley and Atkinson, 1995; Emond, 2005). When I visited the children's ward daily, I would gain consenting children's permission to sit beside them. I would take my cue from the children,

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[114] Carnevale et al (2008:21) also advocated a participative role, "children (and family members) should not be regarded as passive 'research objects' to be observed in a disengaged 'objective' manner".

sometimes we chatted, other times we watched television and played games. This enhanced trust and built rapport.[115]

Children often talked about things going on around them during such play activities. These close encounters with children provided a forum for me to observe children's interactions with health professionals. This enabled me to explore observations with children, such as nurses attending to children's observations or doctors coming to see how children were. In line with Hammersley and Atkinson's (2007) contention, the dividing line between participant observation and informal interviewing was often hard to differentiate. There was no sequence to employing participant observations or informal conversations with children. They were very much opportunistic and intertwined. However, this interconnectedness of observations and interviews was extremely important because it contextualised the information elicited from children.

Other times, I would sit on empty beds or vacant chairs in the room and watch what was going on around me. Sometimes, I wandered up and down the corridor peering into different rooms through the windows. I moved from room to room depending on where consenting children were, and what activities were going on. Often, I joined children's friendly banter, watched television, DVDs and played games with them. I even started to learn how to play the play-station and game-boy. As children came to know me they often approached me to ask me what I was doing, was I going to do some work with them on the project today and often just to chat and show me some tricks or tell me some jokes. Sometimes when I left the ward, to write some notes, on my return staff would inform me that the children were looking for me. Children also frequently asked me about myself,

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[115] I learned from my pilot work the danger of developing over rapport, which could have an impact on attaining authentic information. Another factor was the short child patient stays (high turnover). Each day it felt like beginning a new, because child participants continuously changed, thus relationships were only transitory. This differs to other ethnographies where *informants* mainly remain the same over the course of the fieldwork (as opposed to rapidly changing as child participants in this study did). This was one reason why I 'hung around' on the children's ward and spent intensive time period on the ward to observe and engage informally with children to capture as much details before they were discharged. Engagement in play activities and incorporation of participatory activities, outlined later, assisted with establishing trust and rapport in this short time frame, also highlighted by Coad (2005; 2006; 2007).

where did I live, what car did I have and how my work in college was going.[116] See Appendix 26 for field note extracts related to my role.

I was someone to relieve boredom and a distraction. Parents often saw me as someone to keep their child company while they were not there. It put parents at ease knowing their child was not alone. One might regard this as a form of reciprocity (playing with children, keeping them company and relieving boredom). Another type of potential reciprocity was children (and parents) seeking information from me. Children demonstrated their desire for information when they asked me questions about hospital and what was going on. I became a source of information not only for the children, but also for their parents. I often also spent a substantial amount of time talking to parents. This is perhaps not surprising as parents tried to get to know me, but also parents used this opportunity to vent their views.

While I did not directly explore the views of the staff members, in terms of how they felt about my presence, they were welcoming, openly greeted me on arrival to the ward and were fully supportive in terms of suggesting suitable children who might, or might not, meet the study's inclusion criteria. Throughout my period of data collection, I was not part of the ward team and did not perform any hands on nursing duties. I considered this early in my study and felt it was important to create some space between my role as researcher and nurse. I felt that if I helped staff, children might see me as a staff member, or in allegiance with staff, and be less likely to disclose. I dressed in ordinary-street clothes. This prevented my identification by children as a nurse. However, there were occasions when I had to intervene. Staff did not approach me to ask for my help but sometimes I felt guilty when they appeared to be busy rushing around and I was sitting, chatting and playing with the children. The times when I did intervene were on occasions when I felt compelled to help, for example when a child was sick, when a student looked nervous and in need of some assistance or when a parent needed another hand. Essentially, it was about balancing the fact that by my intervening I might in some way

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[116] Mandell (1988) reported similar issues with children asking questions about whom she was and what she was doing and equated this with children themselves acting as gatekeepers.

disrupt the natural setting, but on the other hand as a nurse it would be unethical not to intervene should a child, parent or nurse require assistance. My intervening could in some way also be interperted as a form of reciprocity (helping the staff and parents out for allowing me spend time in their environment with their child patients/children). On completion of this thesis, I returned to the children's ward to feedback key findings, conclusions and recommendations. On my return staff were receptive and eager to hear about the study outcomes. This verbal feedback will be supplemented with a written executive summary of the study.

Despite wondering what it was I was observing and doing with the children, throughout my time on the children's ward, staff members were friendly and chatted to me occasionally mostly asking me how the research was progressing and asking *was I getting what I wanted.* It was not surprising that my work provoked curiosity. I was conscious of my presence when staff attended to children, not wanting to get in their way. I found it interesting that some staff felt the same towards me when I was with children they were attending. For example, a comment passed to me by a nurse, who arrived to attend to a child's vital signs, was *I don't want to get in your way.* As can be seen from the above description I was not merely a passive observer but a moderate-active, reactive and interactive participant on the children's ward.[117] As Graue and Walsh (1998:91) vividly described:

> "Data are not out there, waiting, like tomatoes on a vine, to be picked. Acquiring data is a very active, creative, improvisational process. Data must be generated before they can be collected. If research is the process of soaking and poking, we emphasise the poking over the soaking, or better, first poke and then soak. The

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[117] I use the term 'moderate-active' here because I am mindful of Spradley's (1980) types of participation (complete, active, moderate, passive and non-participation), all of which indicate different degrees of researcher involvement, both with people and in activities observed. While I saw myself as an active participant, Spradley (1980:60) defines an active participant as seeking "to do what other people are doing". I did not believe that it was possible for me to 'fully do' what child participants were doing, for to do this I would have had to become a child patient and this was and never would be possible, in my adult state. Thus, I use the term moderate alongside active. Spradley (1980:60) describes moderate participation as maintaining a "balance between being an insider and an outsider, between participation and observation". I feel this illustrates where I attempted to be, however neglects to portray my 'active' participation and 'active' observation role, thus, I decided to combine the term active with moderate. I go a step further here also to include the terms 'reactive' and 'interactive' because not only did I interact with the child participants; I interacted with and was reactive to the setting and child participants.

> researcher is not a fly on the wall or a frog in the pocket. The researcher is there. She cannot be otherwise. She is in the mix."

I could equate with this view but contrasting with this need to '*poke*' is the need to '*hang out*', as Zaman (2008:148) nicely stated:

> "Collecting data is like catching a butterfly; if you run after it, it flees, but if you sit quietly, the butterfly sits right on your head."

One main concern often raised in relation to observational research is the effect of the observer on the observed. Through his or her very presence, the observer can disturb the natural environment and trigger a change in typical human behaviour. It is possible that at times children and health professionals could have altered their behaviour in my presence. However, I believe that my ad hoc coming and going, the busy noisy real life environment and the prolonged time spent on the children's ward in some way combated any sustainability in behaviour changes (Carnevale et al, 2008). As Fetterman (1998:36) contended "given time, people forget their 'company' behavior and fall back into familiar patterns of behavior."

#### **4.12.1.3.** *Insider versus outsider*

Debates about negotiating roles and boundaries are not new within ethnographic studies (see Hume and Mulcock, 2004).[118] Essentially debates centre on the blurriness of *insider* versus *outsider*. Hume and Mulcock (2004:xi) contended "the ethnographer must be able to see with the eyes of an outsider as well as the eyes of an insider, although both views, are of course, only ever partial". In the context of this study, children and my self were both simultaneously insider and outsider. I was a professional insider (as a nurse), but an outsider to this specific setting (previously worked in caring for neonates and infants). Children entered the hospital ward as outsiders, unless previously exposed to a hospital setting (even then it might have been a different setting, within a different context and a different point in time). They became insiders, or perhaps natives, as child patients. However, this was not their truly 'native' home setting. But also children were insiders,

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[118] Indeed, Hume and Mulcock (2004) highlight the numerous dichotomies inherent within ethnography, most notably, insider-outsider, self-others, participant-observer, subjectivity-objectivity and intimacy-distance.

as children, whereas I was an insider as an adult - both of us outsiders to each other's worlds. Thus, the dividing line was blurred since we were both insiders and outsiders at the same time. As partial insiders, children's stories might have been limited, however regardless this was their transitory experience of attending the children's ward. Further, while my partial insider status might have clouded my taken for granted knowledge, on the contrary my insight enabled me to understand the stories children told me about their hospital experiences, the meaning of nursing routines and the medical terminology, and explore these with child patients from their perspective.

### **4.12.2.** Informal conversations

Interviews are an extremely important method of data collection within ethnography to capture the *emic* or *native* perspective (Malinoswki, 1922). Interviewing children allows them the opportunity to express their subjective views and experiences (Kortesluoma, Hentinen and Nikkonen, 2003). Interviews can range from spontaneous informal unstructured conversations to structured formally arranged (Rich, 1968), all of which fit within an ethnographic approach. I did not consider the conventional formal style commonly used with adults appropriate for conversing with children (Ireland and Holloway, 1996). The interview context has a profound impact on the child's ability to communicate (Steward et al, 1993; Kortesluoma, Hentinen and Nikkonen, 2003). Children may perceive questions posed by an adult as a test and answer what they perceive to be the correct answer rather than their own personal thoughts (McCrum and Bernal, 1994; Mahon et al, 1996; Hill, Laybourn and Borland, 1996). I selected the informal conversational style because during my pilot work it became evident that avoiding a rigid question answer framework was more suited to permitting free and natural discussion of children's unique perspectives[119] (McCrum and Bernal, 1994; Ireland and Holloway, 1996; Hill, Laybourn and Borland, 1996; Docherty and Sandelowski, 1999; Darlington and Scott, 2002). Additionally, the children's ward setting did not lend itself to conducting formal structured interviews.

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[119] Although conversational in style, these interactions differed slightly from everyday ordinary conversations because I did have a focus, to explore children's perspective of communication on children's ward. Thus, there was the need to incorporate some semi-structured questions.

Conversations took place spontaneously with child participants on the open ward, whenever and wherever (bedside, corridor, play area) the opportunity arose. This enabled me to capture a holistic picture of what was going on around the children on the ward and to discuss 'here and now' experiences with them. I believe this facilitated children's recall. Conversations were mostly on a one to one basis, however on a few occasions two or more children interacted together to provide fruitful data. Conversations lasted anything from a few minutes up to one hour and I met a number of children on more than one occasion. As mentioned previously, sometimes parents stayed while I was playing and chatting with the children, others used the opportunity to take a break.

In these informal conversations, I usually began with a general open question asking the children to tell me why they had come into hospital (see Appendix 27) (or if it was a follow up encounter with children then I often opened the conversation by asking them about what had happened since I last met them). I structured questions around children's daily concrete experiences of what was happening to them in hospital to gather their personal perspective (Hill, Laybourn and Borland, 1996; Docherty and Sandelowski, 1999; Darlington and Scott, 2002). I interspersed some structured questions into the conversations to explore specific issues in relation to communication[120] (e.g. tell me about when the doctor/nurse came to see you, what kind of things does the doctor/nurse talk to you about/tell you). Some children responded better to more direct questions. I avoided interrupting children when they were talking and waited for natural pauses. Nurses and doctors attending to children's care often interrupted my conversations with children. This affected the flow of the conversation. However, these interruptions provided invaluable contextual information and topics for discussion with the children. Furthermore, as semi-participant with children I was able to clarify with them what I had observed happening between them and health professionals, thereby consider my *etic* perspective along with their *emic* perspective.

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[120] Hill, Laybourn and Borland (1996) recommended achieving a balance between structure and flexibility. This is pertinent to allow children a degree of control to set their own agenda but also to enable the researcher to cover topics relevant to the research.

Despite taking cognisance of children's cognitive and linguistic stage of development when phrasing questions (Steward et al, 1993; Hill, Laybourn and Borland, 1996; Ireland and Holloway, 1996; Mahon et al, 1996; Kortesluoma, Hentinen and Nikkonen, 2003), at times it was clear that children misinterpreted my questions. In such instances, I rephrased my questions with words children had used. Parents also helped with rephrasing. Furthermore, to ensure I was correctly interpreting what children were saying to me I frequently paraphrased back to them what they were saying every so often during the conversations, thus clarifying meaning with them. I summarised what we had discussed at the end of long conversations. This enhanced my recall for writing initial field notes immediately after these conversations. At one stage I did try to jot notes at the time of informal conversations with children. However, I found that I was more conscious about trying to record what children were saying on paper, rather than actually actively listening to what children were saying and thinking about their responses, therefore I abandoned this idea.

I assured children there were no right or wrong answers and everything they would say was important (Kortesluoma, Hentinen and Nikkonen, 2003). Some children (generally older, although not exclusively) were more confident, articulate and spoke more freely than others, who were shyer, less articulate and tended to respond with shorter and less in-depth answers. A few children appeared reluctant to talk, answered monosyllabically or with '*I don't know*' answers. Drawing on McCrum and Bernal (1994) contentions, perhaps children may not have understood what I expected of them or they may not have wanted to take part (as previously mentioned in Section 4.10.1.4).[121] On reflection, the children that this happened with were in the early stages of my fieldwork or were children whom I did not get to spend time with to build rapport. It is clearly documented that children's participation efficacy is enhanced by preparation and familiarity (Steward et al, 1993; McCrum and Bernal, 1994; Hill, Laybourn and Borland, 1996; Kortesluoma, Hentinen and Nikkonen, 2003). Children are naturally cautious with strangers and may

[121] Children exercise their power by not responding and deciding what they do or do not want to talk about (Robinson and Kellert, 2004; Greene and Hill, 2005).

take a while to develop trust (McCrum and Bernal, 1994). A variety of rapport building tools and ice-breakers have been used by researchers such as introductions, name labels, about myself, and drawings (Hill, Laybourn and Borland, 1996; Balen et al, 2000/2001; Kortesluoma, Hentinen and Nikkonen, 2003). For me, my role as semi-participant observer greatly enhanced building rapport with children (Appendix 28). This role enabled me to spend time playing and interacting with children, prior to and alongside data collection. It was an inherent part of my fieldwork and not seen as separate or a once off endeavour. This gave me time to get to know the children and allow them to get to know me. In an attempt to enhance less prolific conversations (and focus more specifically on the elusive/abstract concept of communication), I incorporated some innovative participatory tools such as drawings and a stick-a-star quiz (referred to below); as often children become bored with mere verbal interaction.

### **4.12.3.** Participatory activities

Participatory activities enhance rapport building, comprehensive interactions (aids expression of views through an alternative medium), children's attention span, increase control and choice, recognise children's individual abilities and interests, and divert focus away from the adult researcher (Steward et al, 1993; Mahon et al, 1996; Hill, Laybourn and Borland, 1996; Punch, 2002a; Coad, 2005; 2007; Aldiss et al, 2008). The specific participatory activities employed within this study were the draw and write (or tell) technique and a stick-a-star quiz.

Taking cognisance of children's maturity, individual interests and preferences, these activities may not be suitable for all children.[122] For instance, the stick-a-star quiz was particularly valuable for children in the middle age range of 8-12 years. Children over 12 years tended to be happy to just sit and chat; this was sometimes alongside playing the game-boy or play-station. Children chose themselves if they would like to draw, write, complete the stick-a-star quiz or just chat alongside playing. Again, to avoid children

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[122] For example, even young children in Aldiss et al's (2008) study found puppets babyish highlighting the need for a range of methods and flexibility in their use.

viewing the participatory activities as tests, I assured them there were no right or wrong answers. Photocopies of children's drawings and stick-a-star quiz were returned to them if they wanted them (Coad, 2007).[123] I found these participatory activities valuable for giving children something concrete and active to focus on, rather than just sitting passively talking. These activities proved to be a good stimulus for interactive dialogue, used in conjunction with the informal conversations and semi-participant observations (Coad, 2007).

#### **4.12.3.1**. *Draw and write (or tell)*

The draw and write technique involves, as it name suggests, the child drawing a picture in response to a theme and writing down any associated ideas. A variety of disciplines, such as, developmental psychology, anthropology, health education, mental health and geography, employ drawing, as a stand-alone tool, a discussion starter, an icebreaker, and/or incentive at the end of interviews. Others use it as part of a wider interview schedule to empower children to express their views.[124] This was how I employed the use of drawings in this thesis. While the employment of drawings and other participatory activities are not without their challenges, two key issues help to overcome difficulties. Firstly, integrating the use of these participatory activities alongside interviews/conversations and secondly, spending time with children once they have completed their drawing to enable children to interpret their own drawing through their verbal and written accounts (Smith and Callery, 2005; Coad, 2007), both of which I did.

If children wished to draw, I gave them some A4 sheets of white paper, pencils and colours. I reiterated to children that it was not an art test, it did not have to be good and they could draw whatever they wanted (Coad, 2005; 2007). I did provide some suggestions such as inviting children to draw scenes and write stories about when nurses and doctors came to talk to them (Pridmore and Bendelow, 1995; Bradding and Horstman, 1999; Horstman, 2006). Once children had finished drawing, I invited them to

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[123] Giving children choice and applying participatory techniques in a flexible manner helps somewhat to redress the adult researcher child participant power imbalance (Coad, 2007).

[124] See Pridmore and Bendelow (1995); Hill, Laybourn and Borland (1996); Stefanaton and Bowler (1997); Backett Milburn and McKie (1999); Kortesluoma, Hentinen and Nikkonen (2003); Coad (2007)

give their picture a name and either write something about the picture (for e.g. what the child and other people in the picture were doing, thinking and feeling) or to tell a story about the drawing. I used this as a point of conversation with children to open further discussion. Sometimes if children appeared reluctant to talk, I would ask questions like, who are the people in the picture, what are the people in the picture doing, and what are people in picture saying?

#### **4.12.3.2.** *Stick-a-star quiz*

I devised and used a stick-a-star quiz about some aspects of communication with health professionals. A primary school teacher reviewed the stick-a-star quiz and I piloted it with the children from the advisory group. The stick-a-star quiz provided children with a legitimate activity to engage in, in addition to providing structural guidance to help focus the informal conversations more specifically on aspects of communication.

**Stick-a-Star Quiz 1: Sample**



Stick a Star — 1 Star = none / never; 2 Stars = a little; 3 Stars = some; 4 Stars = a lot

| How many stars do you think? | 1 star none/never | 2 stars a little | 3 stars some | 4 stars a lot |
|---|---|---|---|---|
| How much does the doctor talk to you? | | | | |
| How much information does the doctor give you? | | | | |
| How much of what the doctor tells you do you understand? | | | | |
| How much does the doctor allow you to speak / have your say? | | | | |
| How much does the doctor listen to you? | | | | |
| How much does the nurse talk to you? | | | | |
| How much information does the nurse give you? | | | | |
| How much of what the nurse tells you do you understand? | | | | |
| How much does the nurse allow you to speak / have your say? | | | | |
| How much does the nurse listen to you? | | | | |



In the stick-a-star quiz, displayed above (stick-a-star quiz 1), I presented children with a series of open-ended questions about communicating with health professionals. Examples of which are, how much information does the nurse give you and how much does the nurse listen to you? To answer these questions, children allocated one (none/never), two (a little), three (some) or four stars (a lot) to health professionals. I talked the children through the stick-a-star quiz by saying, if you feel the nurse gave you lots of information she gets four stars, if the nurse gave you some information she gets three stars and so on.

Once children had stuck their stars I further explored with children, why they allocated the number of stars they did and how health professionals could obtain more stars. For example, if a child said that he/she was given some information by the nurse, and thus allocated the nurse three stars accordingly, I would ask the child to tell me what specific information the nurse gave to him/her to get three stars. If the child said he/she was given little information and only allocated the nurse two stars I might ask what information he/she was given but also what else could the nurse have told him/her so that she [nurse] could get more stars (three or four). Similarly in relation to doctors listening to children, once children had allocated their number of stars and pending whether they felt listened to or not I would ask them to give me an example of when they felt the doctor listened or did not listen to them (see Appendix 29). The idea for this activity stemmed from a pots and beans activity described and used by O'Kane (2000). [125]

Another reason why I chose to employ some participatory techniques was to help minimise the researcher-child participant power imbalance. It is widely argued that the use of task-based activities distract children's attention away from the researcher, placing the interaction between the child and activity; allowing for children's greater participation and control (Mahon et al, 1996; Mauthner, 1997; Punch, 2002a; Coad, 2007; Aldiss et al, 2008). However, now I re-consider this contention and raise the question; can this power divide be minimised, and if so, to what extent? Indeed, one key issue missing from this debate is the power of children themselves. Despite this, I believe the employment of a

[125] The pots and beans activity ascertained children's views about their participation in review meetings as well as their participation in the decision-making study.

variety of innovative participatory child-friendly activities contributed some way to enhancing trustworthiness, ethical and methodological issues. However, it was crucial to use these activities in context and continuous dialogue with children. The goal was to achieve a balance between creative instruments and commonplace conversation. As with all methods, there was the need to be critically aware of individual methods strengths and weaknesses (Appendix 30).

### **4.12.4.** Documentary evidence

The final source of data collected was documentary evidence (Hammersley and Atkinson, 1995). I collated documents relating to communication on the children's ward, for instance, information sheets for children on different aspects of their care or condition. I sourced one information booklet. This information booklet was the hospital pre-admission booklet developed for children who attend a monthly pre-admission club programme (arranged for children with upcoming elective admissions). One of the forty-nine child participants mentioned receiving this booklet. I also collated information from the children's ward policies, guidelines and philosophies that would help me in adequately detailing background particulars of Barda Linbh (see chapter 5). After some time in Barda Linbh, I became away of the admission assessment form (which was completed for all children admitted to the children's ward) as a potential source of data. This admission assessment form assessed children's everyday routine (and altered routine) according to the activities of daily living.[126] I was interested in and studied one specific section of this form entitled *communication.* For two thirds of the child participants I extracted and transcribed literally the written text within the communication section of this admission documentation and used it as data (Hammersley and Atkinson, 1995). I used these documents to substantiate and contextualise content from the other data sources.

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[126] Activities of daily living include, sleeping and comfort, eating and drinking, breathing, elimination, washing and dressing, safety, play and learning, mobility, emotional well-being and communication.

### 4.13. Recording Field Notes: *being there is not enough*

Graue and Walsh (1998:132) and Hammersley and Atkinson (1995:175) respectively recommended; "assume you will remember nothing. Always over-annotate at every stage of the research process" because inadequate note taking "will be like using an expensive camera with poor quality film". I handwrote and typed field notes, the traditional means of recording data in ethnographic research, as soon as possible after each of my field visits to Barda Linbh (Hammersley and Atkinson, 1995; Emerson, Fretz and Shaw, 1995; 2001[127]). I developed these field notes from brief jottings taken while in the field. I withdrew from the ward at frequent intervals (toilet, stairway) throughout my field visits to write key points in a pocket-sized notebook to facilitate later recall (often referred to as memory sparkers).[128] Other times, I wrote extensive notes (expanded from brief jottings), especially after long periods of observations or conversation with children. This often took place in the hospital library, a nearby coffee shop or a friend's office. Generally, I wrote notes retrospectively because it felt inappropriate and incongruent with my role/positioning in the social setting to write notes while on the children's ward. If I did make jotting on the ward I did so out on the corridor and away from child participants. I then transformed and expanded my handwritten jottings and more extensive notes into more substantive typed field notes in a word processing package, as soon as possible after each ward visit (usually on same day, first thing the next morning and no later than 24 hours later).[129] Once typed, I edited these field notes a number of times on reading and rereading. I often added recalls of forgotten information at later stages (Lofland and Lofland, 1995). At the beginning, it was sometimes difficult to know what and how much to record. I was aware of Johnson's (1995) suggestion to record the obvious, the boring, and the interesting. This was important because, as a nurse, I was partially a hospital 'native'. I was mindful not to neglect the mundane.

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[127] Emerson, Fretz and Shaw (1995; 2001) offer guidance on field note recording.
[128] I began with short periods of observation taking frequent breaks to jot down notes to help with recall.
[129] Graue and Walsh (1998) referred to this as the construction of a data record. Initially, it is a descriptive process and while interpretation is ongoing, interpretation only becomes a primary activity when the data record is constructed.

Initially, I recorded all field notes chronologically, in a single folder. Typed field notes entailed descriptive accounts of events/interactions observed and records of my informal conversations (including participatory techniques) with child participants. I typed observational (general observations and observations related to specific key phenomenon) and conversational records into separate word documents. To write up my observational field notes I mentally used the framework of asking who, what, where, when, why and how (Graue and Walsh, 1998), in addition to the guidelines offered by Spradley and Merriam on what to observe (Appendix 24). This enabled me to think about and recall interactions I had observed between children and health professionals, who was involved in these interactions, what had taken place during the interaction, where, when and why it had taken place. I also recorded notes about the context and ward environment, routine activities and incorporated sketches of the environment as deemed appropriate. Incorporated into the concrete descriptions, (but recognised as separate and identified by using a system to mark and separate different type of material e.g. round, square, double brackets), I recorded personal impressions, feelings and inferences, reflections on my role, methods used, general challenges, emerging interpretative ideas, and reminders to look for any further additional information (Lofland and Lofland, 1995) (see Appendix 31).

After my informal conversations with individual child participants, I left the children's ward to write up extensive handwritten notes paraphrasing as much as I could recall immediately after these conversations, which also included children's description of their drawings and responses to questions on the stick-a-star quiz (Johnson, 1995, Emerson, Fretz and Shaw, 1995; 2001). Similar to observational data I then typed and expanded these handwritten notes at a later stage in the day. I did not audio-record these conversations (or any observed interactions) because my conversations took place on the open ward and the background environmental noise and dynamic moving context would cause too much interference (Johnson, 1995; Hammersley, 2008). This initially worried me especially because I would not have 'concrete evidence' of children's actual words and no direct quotes (Deatrick and Fauk, 1991; Fetterman, 1998; Corden and Sainsbury, 2006). How would I present credible verbatim descriptions of children's voices? I was

reassured by Atkinson's (1995:11) debate that, "there is a danger of reducing the scope of qualitative research to those occasions suitable for recording, and of treating transcribed materials as the only source of data". Hammersley and Atkinson (1995) argued even if one does tape-record it is still necessary to construct field notes; for audiotapes fail to capture contextual factors with an overemphasis on the spoken word. Johnson (1995:25) contended that, "it is acceptable to paraphrase what people say provided you are confident that the meaning is the same and you make it clear in the final report that the source is a field note rather than a transcribed interview transcript". Thus, in this thesis all data reported are paraphrased data from my field note constructions and not verbatim quotations.

### 4.14. Withdrawing from the Field

It was often difficult to know how long to spend in Barda Linbh each day. Sometimes, on good days, it was hard to withdraw. While I needed to spend adequate time in the field to become familiar with social processes, there was the risk of spending too long and becoming fatigued, which would make writing up and reflecting upon field notes difficult (Johnson, 1995). I could equate with Johnson's sentiment because I did find time in the field tiring; especially having to return home to type up more extensive field notes and reflect on the data. However, this balance of spending time in the field to gather data and withdrawing to write up (and begin preliminary analysis) field notes was a dilemma I encountered. Short stays and high patient turnovers presented difficulties in meeting children, building rapport, negotiating informed consent and actually spending time with children to gather data. I tried to minimise observer fatigue by taking frequent break and withdrawing at times to begin constructing field notes. This helped me at the end of the day in constructing my data record.

While many talk of the emotional tension of withdrawing completely from the field, I did not really face this. This was possibly because of the high turnover of child patients. Prior to complete withdrawal all child participants had been discharged. Apart from the recommendation of prolonged engagement over a period of months, there is limited explicit agreement about how long one should remain *in the field* for. The time at which I

withdrew from the children's ward felt right. I was not seeing or hearing anything new. I felt I needed to withdraw to attend to data analysis more profoundly (Fetterman, 1998).

### 4.15. Data Analysis and Interpretation

There is no standard formula, recipe, procedure or set of steps for analysing ethnographic data (Hammersley and Atkinson, 2007). The purpose of data analysis, within ethnography, is to identify meanings and functions of human actions and their relationship to local and wider contexts (Hammersley, 2008). Drawing on the work of Hammersley and Atkinson (1995; 2007) data were analysed through grounded theorising, defined as a way of working with any sort of data in order to generate and develop ideas.[130] Analysis is a flexible interactive dialogical activity.[131] While I attempt in some way to paint as realistic a picture as possible of this activity, I believe it fails to capture the dynamic interplay that took place between the data,[132] my self and the literature.

A number of texts, (Hammersley and Atkinson, 1995; Emerson, Fretz and Shaw, 1995; Coffey and Atkinson, 1996; Graue and Walsh, 1998; Strauss and Corbin, 1998), provided structure and direction for deconstructing and reconstructing data through the processes of coding and categorisation. I developed a diagram (Appendix 32) which helped me in maintaining consistency in analysing all data (Sandelowski, 1995). While in this diagram I try to capture the non-linear process with much interconnectedness, it fails to display fully the complexity of the dynamic back and forth movements inherent within the analysis activity (Graneheim and Lundman, 2004).[133]

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[130] The ***grounded theorising*** that Hammersley and Atkinson (2007:159) referred to is an activity, "a way of working with data (of any sort, including quantitative data) in order to generate and develop ideas". A central feature is the constant interplay between data and ideas throughout the research process. Hammersley and Atkinson made it clear that they were referring to an activity, not a procedure with a grounded theory as product. Charmaz and Mitchell (2001:160) stated grounded theory methods offer ethnographers flexible strategies for collecting and analysing data; "no more, no less".

[131] I refer to analysis as an activity as opposed to a process because process has an objectivist undertone with the contention that there are a set of steps to follow. Hammersley and Atkinson (2007) recommended ignoring any such implications. For me, it as more like navigating a complex jigsaw puzzle, often with many or one missing piece, which had to be found, and to do this it often required starting anew again.

[132] By data, I mean field notes comprised of conversations, observations, documents and participatory tools.

[133] At a recent workshop, Hammersley (2008) relayed that to portray this accurately would be impossible. Indeed, it neglects all the scribbling, potentially only understandable to me (Sandelowski, 1995).

The cyclical nature of data collection and analysis is emphasised in ethnography with adequate time factored in for reflection and interpretation, which drives further data collection, and so on (Hammersley and Atkinson, 1995). I was restricted here because of the high and fast child patient turnover. As soon as I had recruited children to participate I had to try spend as much time as I could with these children to engage in semi-participant observations, build rapport and chat informally with them. Therefore, data collection was often intense, followed by a concentrated period of writing field notes. Thus, initially sometimes I felt I did not give adequate time for reflection and interpretation. However, what I neglected to take account of was all the informal reflection and interpretation I engaged in. I continuously thought about the data in everything I did.[134] When I recorded descriptive field notes, daily, I began data analysis by inserting into these my reflections, distinguished by double round brackets ((my thoughts)) (see Appendices 25, 27, 29). After typing my field notes, I read and reread them and thought about them to help me in my direction the next day. However, it was not until I left the field completely that a deeper and lengthy period of data analysis took place (Emerson, Fretz and Shaw, 1995).

Initially, I coded field notes from conversations (including participatory techniques) in an attempt to stay close to the voice of the child (*emic*). Alongside the conversations, I coded the participatory techniques (draw and write and stick-a-star-quiz). I coded these according to the field notes I had written based on children's descriptions of their drawing (or children's written words) and the conversations that took place when children told me about how many stars they were giving and why. Then I separately coded my (*etic*) observational field notes. Following this, I amalgamated all codes converging both *emic* and *etic* perspectives. Later, I created a folder for each child participant containing individual conversations and observations pertinent to that child, which I then jointly examined to identify comparable and contradictory issues. Next, I examined the data across two different age brackets, 6-11 years and 12-16 years, in an attempt to identify any stark differences between younger and older children.

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[134] Most notably, it was often while jogging or in my sleep that many ideas and thoughts sprung to mind, so it was always valuable to have a notepad at hand.

I continuously worked manually with paper copies of my typed field notes and then I worked with the data using Microsoft Word. The process began with open coding.[135] Due to the volume of data and diverse sources, it was difficult to read the data in its entirety. However, large chunks of field notes[136] for a number of child participant conversations, observations and participatory techniques were simultaneous reviewed and read, and reread, in an attempt to get a sense of *what's going on here?* Then, I examined further field note chunks until I had read all in their entirety to get a sense of the whole (Sandelowski, 1995). Following this, I recorded handwritten marginal notes on paper copies in an attempt to decipher *what is it saying?* I jotted ideas and thoughts in the margins. On further reading, I assigned open codes by examining data microscopically by line, sentence and paragraph (Appendix 33). I also used the comment facility on Microsoft Word documents to go through and code field notes. I went through the documents a number of times and each time tried to see different or similar things. I then used a number of Microsoft Word documents to de-contextualise the data electronically through the process of coding. Here I cut and pasted for each similar code into a separate document.

Following on from open coding, I examined each separate coded document for similarities and grouped these together to form larger ideas (often called concepts). I eventually grouped a number of these codes and larger ideas together to form categories (Appendix 34). This began the process of axial coding whereby I started to rebuild the fractured data. I continually compared and contrasted codes and ideas to build these categories. Then I worked at defining the categories and developing them further to identify their dimensions and properties. I found this part of data analysis a very difficult and challenging process. The variety of terminology used became more of a hindrance than a help. I became engrossed in trying to discover and explain what was a category or a sub-category, or a property, or a dimension. Eventually I abandoned the use of this

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[135] Open coding involves coding for everything and anything that seems potentially relevant. It is a dynamic and fluid process, which opens up the data, exposes ideas and meanings and helps to reduce data to a workable size (Coffey and Atkinson, 1996; Strauss and Corbin, 1998)

[136] While I state I dealt with data in large chunks, I completed all processes here for all data.

terminology and just worked with dimensions of themes or patterns that were emerging.[137] In addition to this, the volume of disjointed Microsoft Word documents became challenging. Therefore, to assist me further with data management I employed the qualitative computer data analysis software package NUD*IST (non-numerical, unstructured, data: indexing, searching and theorising). At first, I found this valuable, it ensured that I was very familiar with the data and assisted me with writing descriptions and memos, which could be easily retrieved according to the codes or categories to which they were directly associated. However, to move beyond coding to interpretation I returned to manual analysis and the use of Microsoft Word.[138] This involved a period of recurrently working with the data, asking questions (who, what, where, when, why, how), recording memos[139] (my thinking, ideas and interpretations), collapsing and reforming categories (Appendices 35, 36, 37, 38). I found Strauss and Corbin's (1998:97) concept of the *'waving red flag'* useful in terms of standing back and thinking somewhat neutrally about the data (Appendix 36).

> "Whenever we hear the terms "always" and "never" these should wave a red flag in our minds. Remember that we are thinking dimensional ranges, and "always", "never", "everyone", and "no other way" each represent only one point along that continuum. We want to understand the dimensional variations such as "sometimes" and "occasionally" and the conditions that lead to those."

To assist with data interpretation I also drew upon literature and experience, most notably communication theories. For example, concepts such as premature reassurance, optimistic assertion and blocking strategies, such as distancing, frequently emerge in adult communication literature and communication textbooks. I did not use literature as data. Instead, I used it to help me examine and explain data and emerging concepts (Hammersley and Atkinson, 1995). You will see this in my findings chapter where I

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[137] More simply put, Graneheim and Lundman (2004) referred to manifest and latent content of text. Manifest content refers to what the text is saying (category) and latent content refers to what the text is talking about, the relationship aspect and underlying meaning (theme). Both deal with interpretation but at varying degrees of depth and abstraction.

[138] Johnson (1997b) urged caution in using computer packages for qualitative analysis, that while valuable we must avoid a reversion to counting concepts rather than thinking about them. Graue and Walsh (1998) expressed similar sentiments highlighting that computer packages are rather like high tech scissors and folders but they do not ensure that you get it right or protect you from getting it wrong.

[139] Birks, Chapman and Francis's (2008) recent paper offers valuable guidance on writing memos for qualitative research in four areas, M: mapping research activities, E: extracting meaning from data, M: maintaining momentum, and O: opening communication.

incorporated some literature to help explain the data and show similar or different concepts from other areas.

In getting to the final stage, Strauss and Corbin's (1998) suggestion of organising data under one single overarching category (referred to as selective coding) helped. Consequently, I pulled all existing categories together under one central or core category to explain the emergent findings from this research, which was *"visible-ness"*. This helped to connect the different dimensions together and explain how they all related to the core, *"visible-ness"*, construct. To get to the final completed version of the *"visible-ness"* construct I returned to one of my guiding frameworks, the trans-circular model of communication. Drawing on the three main concepts of this model (process, message, and context) enabled me to restructure the data in a new way. I was conscious not to force the data to fit the framework and ensured I remained faithful to the data by continuously returning to the raw data (my original field notes) (Sandelowski, 1995)[140] (Appendix 39, 40). This illustrates how findings correspond with pre-existing communication models (see findings chapter 6). After this, I drew upon my second theoretical framework, the principles of Bronfenbrenner's ecological model of human development to try to explain the relationship of the findings to wider contextual influences (see discussion chapter 7).

I want to draw attention to a few challenges I faced over the course of my data analysis, most notably in relation to the analysis of children's data. First, when I got to the stage of moving beyond description and coding to interpretation I was afraid of imposing my interpretations on the data and losing the voice of the child (here again we see the emic *versus* etic debate arising). Bricher (1999a) suggested that adult researchers might not be able to interpret fully children's data because of generational and cultural differences. Perhaps, having children involved in this process would have helped (see Coad and Evans, 2008). Still, interestingly, in one case example, Coad and Evans (2008) highlighted child analysts might impose their own interpretations on the data. Christensen (2005, personal communication) suggested the way to go about analysing

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[140] Sandelowski (1993) stated that theory fits well when it easily allows for comparison to its main components and can prove useful as a framework for organising data for re-presentation.

data produced by children is in principle the same as how one would handle data in any other ethnographic study. Furthermore, Punch (1998) highlighted that children's generational position tends to mean that an adult has access to wider knowledge. This is no different from other types of research with adult participants. This relates not only to interpreting children's data, but also to ethnography itself. There is a tension between producing 'thick descriptions' to display it 'like it is' and actually grounded theorising. If we merely work towards 'telling it as it is', we risk having implicit and underdeveloped data (Hammersley and Atkinson, 1995). This brings us back to the emic-etic debate, or the dichotomy of trying to remain faithful to the raw data but simultaneously recreating it to enable us to see the phenomenon under investigation in a new way (Sandelowski, 1995; Graneheim and Lundman, 2004). A second related concern was, how do I get in-depth data from children's limited responses?[141] A valuable suggestion to help me over this hurdle was to think more about getting in-depth analysis and going beyond the directness of the responses themselves. Christensen (2005, personal communication) highlighted the importance of triangulation of data which would enable me to achieve an in-depth understanding of my field from different angles and examine the authenticity of my understanding and interpretations.

### 4.16. Judging Quality: Trustworthiness

Spencer et al (2003:38) highlighted that "the subject of 'qualitative criteria' is a hotly-debated issue". Concerns about *validity, reliability, objectivity, rigour*, *robustness*, *credibility*, *goodness, quality, trustworthiness,* of qualitative inquiry are widespread, with no formally agreed standards for judging quality in qualitative research.[142] Hammersley (1992) does not believe in the application of algorithmic criteria. He does not reject the notion of quality criteria for judging qualitative inquiry however because it "is essential if

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[141] This related to less articulate children with limited responses, as opposed to more expressive children.

[142] There is a multi-factorial debate about whether, and what, criteria should be used to assess qualitative research (Emden and Sandelowski, 1998; Rolfe, 2006). Some reject criteria altogether (Smith, 1990). Others apply quantitative criteria (LeCompte and Goetz, 1982). Others advocate for reformulation, or development of alternative criteria (Lincoln and Guba, 1985; Leininger, 1994; Appleton, 1995; Cutliffe and McKenna, 1999; Porter 2007). The most frequently cited reformulated criteria for assessing quality in naturalistic research are those offered by Lincoln and Guba (1985), which are, credibility, applicability, consistency and neutrality. I believe it is hard to separate out different trustworthy criteria because I see them as intertwined and interrelated.

qualitative research is to be of any value, since otherwise it allows no rational basis for distinctions between sound and unsound, and more and less valuable, accounts" (Hammersley, 1992:61).

The dominant tendency is to search for overarching criteria to judge the quality of all types of qualitative inquiry regardless of epistemological assumptions inherent within them. This neglects the uniqueness and divergence of different perspectives and often results in the inaccurate application of criteria to judge particular studies (Leininger, 1994). What is important then is that each individual must become clear about the different types of criteria that can be used to judge the quality of their research (Koch, 1994) and how these criteria fit with their underpinning philosophical assumptions (Emden and Sandelowski, 1998). For instance, there is no methodological orthodoxy in qualitative research, including ethnography (Muecke, 1994), yet quality criteria are essentially 'procedural' (Schwandt, 1996). This leads to a dilemma because:

> "If rigour is understood only in terms of a structured, measurable, systemized, ordered, uniform and neutral approach, then other research methods, that allow flexibility, contradictions, incompleteness, or values will always appear "sloppy", epitomizing everything that is "nonrigour" and therefore lacking credibility" (Davies and Dodd, 2002:280).

Although, there is now an acceptance of the researchers subjective presence and active involvement in data construction and interpretation (Finlay, 2003), there is still the inclination to objectify the approach employed (Schwandt, 1996).[143] The philosophical assumptions underpinning this thesis recognise that we can never know the extent to which an account is true with certainty because it accepts that there are multiple constructions of social reality. There is no single meaning, interpretation or universal application (Graneheim and Lundman, 2004). Therefore, there can be no correct or incorrect procedure because it is simply a case of one interpretation of reality *versus* another. The aim is to provide a re-presentation, not reproduction, of reality (Hammersley, 1992) and the multiple perspectives that exist (Appleton and King, 2002).

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[143] Perhaps this relates to an obsession with *justification* as highlighted by Sandelowski (2008).

In terms of data collection, three processes, prolonged engagement, persistent observations and triangulation of data sources, assisted me in re-presenting the reality of communication on the children's ward from multiple child perspectives (alongside my perspective and interpretations). I visited the children's ward intensively over a period of four months and engaged in persistent observation during this time. This ensured that I spend sufficient time[144] within the children's ward to appreciate and understand the context within which communication took place between children and health professionals. This also ensured that I spent adequate time to take account of any reactivity distortions and assisted with trust building. Diligence in recording field notes as soon as possible after ward visits helped me with recall and reporting observations as faithfully as possible. Selecting a diverse sample of child participants who had a range of different experiences enabled the representation of different child perspectives (Mackenzie, 1994). The purpose of triangulating multiple data sources, namely observations, conversations and activity based participatory techniques, was not an attempt to illustrate consensus or convergence of perspectives, which carries positivist connotations (Cutliffe and McKenna, 1999). Instead, it was to gain a richer and more comprehensive picture, adding to the credibility of findings (Madill, Jordan and Shirley, 2000). In contrast to narrow breadth, the inherent value in employing an ethnographic approach was the depth of data generated through the integration of both observations and interviews.[145]

The multiple data sources assisted with consideration of socially desirable responses (Mackenzie, 1994). While I did not have doubt about the truthfulness of children's responses, very often concerns about the accuracy, suggestibility, consistency and truthfulness of children's responses are raised (Docherty and Sandelowski, 1999). Punch (1998) highlighted that there is the assumption that children lie and have difficulty distinguishing between reality and fantasy. However, children's imagination does not distract from *accuracy* but confirms it (Ireland and Holloway, 1996). McCrum and

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[144] Time spent in the children's ward was representative of various days of the week and hours of the day.
[145] Being there over an extended time-period, seeing and hearing what was happening, listening to what was said and gaining insight into the broader context where the process of communication occurred.

Bernal (1994) acknowledged that sometimes children might contradict what they said earlier, tell lies and make up stories, but so do adults. Thus, while children may not possess the same competence to communicate as adults, this does not mean that data received from children is in anyway invalid (Rich, 1968). I believe the unstructured, flexible approach and variety of data collection tools utilised in this study enhances the accuracy, truthfulness and reduces the suggestibility of children's responses. For as Waterman, Blades and Spencer (2000; 2001; 2004) reported the question format and interviewer knowledge (social context) affects the accuracy of children's responses. Rich (1968) believed adult controlled and structured interviews and questions barely scrape the surface of what children are able to tell us. If children simply answer adult construed questions without expanding responses to explain what adults did not think to ask, then truth may never be known.

In terms of data analysis, some postulate that participants (member checking) and colleagues (peer debriefing) should verify findings and interpretations (Lincoln and Guba, 1985; Deatrick and Faux, 1991; Mays and Pope, 1995; Cutliffe and McKenna, 1999). Others disagree (Hammersley, 1992; Porter, 2007).[146] Such criteria hold that one can reach some level of agreement. I believe attempts to achieve consensual re-presentation neglects to portray the perspective of the minority. In light of the underlying assumptions of this thesis, that data derive through multiple constructions and researcher-participant interactions, within a specific situational context at a particular point in time[147] I apply such criteria cautiously. Yet, Graneheim and Lundman (2004) defended the value of dialogue among co-researchers, but with emphasis on confirmation not verification. What I did do was a form of informal continual member checking while in the field to follow up and clarify different aspects that I was unclear on, about what children had said or what I had observed. Additionally, I was able to discuss my data with my supervisors.

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[146] Participants may feel it is in their interests not to accept truths or to accept falsehoods, they may themselves not be aware of key features of what happened to them or others, and it omits the social character of the relationship between researcher and participants (Hammersley, 1992). A peer colleague would not have been in the field and thus would not have the in-depth familiarity of the context in which observations and conversations took place.

[147] Meanings that people attach to events may change in different contexts, circumstances and over time (Hammersley and Atkinson, 1995).

I had to explain my thinking and decisions behind choices of lines of enquiry. This stimulated my thinking about things that were potentially missing or that perhaps I was not seeing. I presented emerging categories and themes at various national and international conferences or PhD support groups, both formally and informally. Following these sessions, I would open up the data again and think about it from different angles. These processes enabled me to seek multiple meanings within the data to add breadth and depth to analysis (Tuckett, 2005).

There is much debate about the place; function and use of theoretical frameworks within research (see Section 3.0). Fetterman believes:

> "No study, ethnographic or otherwise, can be conducted without an underlying theory or model. Whether it is an explicit anthropological theory or an implicit personal model about how things work, the researcher's theoretical approach helps define the problem and how to tackle it" (Fetterman, 1998:5).

Maso (2003:46) stated a theoretical framework is a *"hotchpotch of knowledge, experiences, ideas etc."* which enables the researcher to bring his/her assumptions and prejudices to the fore. I began with and sought guidance from two theoretical frameworks (see Section 3.2). I was mindful not to mould interpretations of the data into these frameworks (Sandelowski, 1993; Hammersley and Atkinson, 2007). Therefore, while the two theoretical frameworks helped to format my research questions and give some structure to data collection I did not initially use these to analysis data. Only after I had completed and developed my initial themes did I return to draw upon these frameworks as resources to restructure the data. In doing this, I also referred back to my archived raw data/field notes to validate the final construction. The employment of these frameworks helped to maintain an internal logical flow within this thesis.

There are differing debates about who is responsible for assessing the transferability or relevance of findings to other settings, writer, reader or both reader and writer.[148] In this

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[148] Some advocate for aesthetic, as opposed to epistemic, criteria for judging quality of qualitative studies with the argument that quality judgments can only be made on the way the research report is presented to the reader rather than directly on the research itself (Sandelowski and Barrossa 2002; Rolfe, 2006). Others disagree highlighting the mediation between reader and writer (Porter, 2007). See also Lincoln and Guba (1985), Muecke (1994), Cutliffe and McKenna (1999), Koch (1994), Tuckett (2005).

thesis, I as writer have provided a detailed description of contextual data[149] to enable readers' to make judgments about similarities and differences in order to determine the applicability of data to their settings (Pickler, 2007). I believe that the commission of this research in a real life natural context enhances its transferability. The aforementioned processes of prolonged engagement, persistent observation and method triangulation allowed me to capture vivid descriptions of interactions that took place in the social context of the children's ward and of the voices of children. This enabled me to portray not merely my *etic* researcher interpretation but also the *emic* child perspective. In saying this, I accept the partiality and localization of the findings being mindful of the fact that this study took place in one children's ward, in one children's hospital, at one point in time. This does not mean that the account produced is any less reliable. I do not aim for *replicable* findings over time and across contexts, rather for consistency within my application of practices (Meucke, 1994). I have tried to make each stage of my methodological journey as explicitly visible, realistic and non-idealistic, as possible within the constraints of this thesis (Koch, 1994).

### 4.17. Conclusion

Section A provided an overview of the social positioning of children within research, namely the movement from research *'on'* children to research *'with'* children. Traditionally, adult proxies extensively represented the views of children. In the modern-day, children are viewed as competent participants in the research process. However, it is acknowledged that to take account of children's vulnerability, immaturity and developmental stage, it is vital to employ methods that maximise children's ability to express their views. Ethnography allows for a creative and flexible child-centred investigation. In Section B, I outlined the philosophical and methodological assumptions underpinning this ethnographic inquiry. Essentially, this thesis draws on an ethnographic approach informed by a social constructionist epistemology recognising that knowledge and reality are socially constructed and discovered through researcher-researched

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[149] Detailed outline of setting, child participant recruitment and characteristics, data collection process, my role, analysis and interpretation, and the inclusion of authentic field note extracts to illustrate origin of interpretations.

interactions and relationships. Ontologically, the social constructionist approach taken in this thesis is at once realist and relativist (or according to Martyn Hammersley subtly real). The contention is that knowledge is socially constructed and thus essentially local and specific (relative), reliant on cultural assumptions. Knowledge can exit independently of mind, yet we can only partially come to know about it; judged by reasonable assert-ability. The aim of this mini-processual and particularistic ethnography was to discover the multiple perspectives of child patients. The emphasis was on unravelling the patterns of social behaviours related to the process of communication taking place on the children's ward, in addition to the contextualisation of these social behaviours locally and universally by drawing on a wide range of theoretical perspectives. In Section C, I detailed my experience of *doing* ethnographic fieldwork. Fieldwork took place over an intense four-month period in one children's ward in one specialised children's hospital. During this time, I spent two hundred and forty five hours in one thirty-five bedded children's ward. Forty-nine children, aged six to sixteen years, with a variety of medical and surgical conditions, participated. Data collection occurred through multi-modal methods, namely semi-participant observations, unstructured interviews, draw and write technique, stick-a-star quiz and documentary evidence. I recorded all data in the form of field notes and analysed field notes through grounded theorising, a process of constant dialogical interplay between data, researcher ideas and literature.

Before explicating the emergent findings, in the next chapter I will set the scene by describing in detail the setting where my fieldwork and communication between children and health professionals took place.

# CHAPTER 5: SETTING THE SCENE

## 5.0. Introduction

The purpose of this chapter is to present the environmental scene and daily customs of the KidZ[150] Hospital and Barda Linbh[151] which served as the research field. Describing the original context will allow the reader to judge the transferability of findings, in addition to, assessing how precisely findings represent the reality of the phenomena under study (Koch, 1994; Mackenzie, 1994). As previously highlighted (Section 4.6), sampling in ethnography is more than mere numbers of participants; it also incorporates place and time (Mackenzie, 1994). I constructed the material presented in this chapter from an amalgamation of all modes of data collection, namely, participant observations and informal conversations (including children's drawing) with child participants on the children's ward at the time of data collection. I present both my perspective and that of the child participants. I retrieved additional background information through documentary evidence and personal communication with various hospital personnel. While it is not uncommon for ethnographers to name the setting of their research, access to and ethical approval for the conduction of this study was granted on condition of both child participant and hospital setting anonymity. Therefore, I have omitted or altered any identifiable material, pertaining to both setting and participants (allocated pseudonyms). To set the scene, this chapter begins with presenting some background details about the KidZ Hospital. I follow this by an outline of a 'day in the life' of Barda Linbh.

## 5.1. The KidZ Hospital

The KidZ Hospital is a specialised children's hospital in the Republic of Ireland, which admits children from birth up to 14 years of age. Although, children on reaching their 14th birthday who are already receiving care at the hospital often continue their treatment to its completion there. Inpatient, outpatient, day, emergency and elective cases are catered for; with an annual attendance of over 100,000 children. Over half of these

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[150] The Hospital name was chosen by the child particiants in this study.
[151] Irish: translated the children's ward

children attend the emergency department and the other half the outpatient department. Approximately another 12,000 children are admitted electively, a third of these are day cases. Half of the children admitted to the hospital fall into the age bracket of 0-5 years. A variety of medical and surgical specialities are catered for across a wide range of wards; medical, surgical, infant, toddler, intensive care, high dependency, emergency department, outpatient department and operating theatres. The hospital also features a playroom, school and facilities for parents to stay. In affiliation with third level institutions, the hospital offers training to both undergraduate and postgraduate nurses and doctors in caring for sick children and their families. Facilities are also provided for training students in other disciplines such as physiotherapy, radiography and dietetics, to name a few.

### **5.1.1.** Entering the KidZ hospital

This non-purpose built *hospital* building exhibits its age in its architecture with Georgian remnants. Internally, it could be described as an archaic web of innumerable stairways. The early inspirations of religious orders are evident through various religious statues and photographs. A friendly pleasant atmosphere prevails where everyone seemed to know everyone. Entry to the hospital is commanded by the porters from behind their big desk in the main entrance hall. A 'smile', 'glance', 'hello' or 'good morning' is the usual greeting. Just past the entrance hall, displayed on a wall in the hallway is the unified mission statement of the KidZ hospital. This mission statement promotes a friendly and caring environment where sick children are cared for with '*respect*', '*dignity*' and '*compassion*'.

> "In our friendly and caring environment, we strive to promote the highest quality of care for all with dignity, compassion and respect. We value our staff and encourage their development" (Extract from the hospital mission statement).

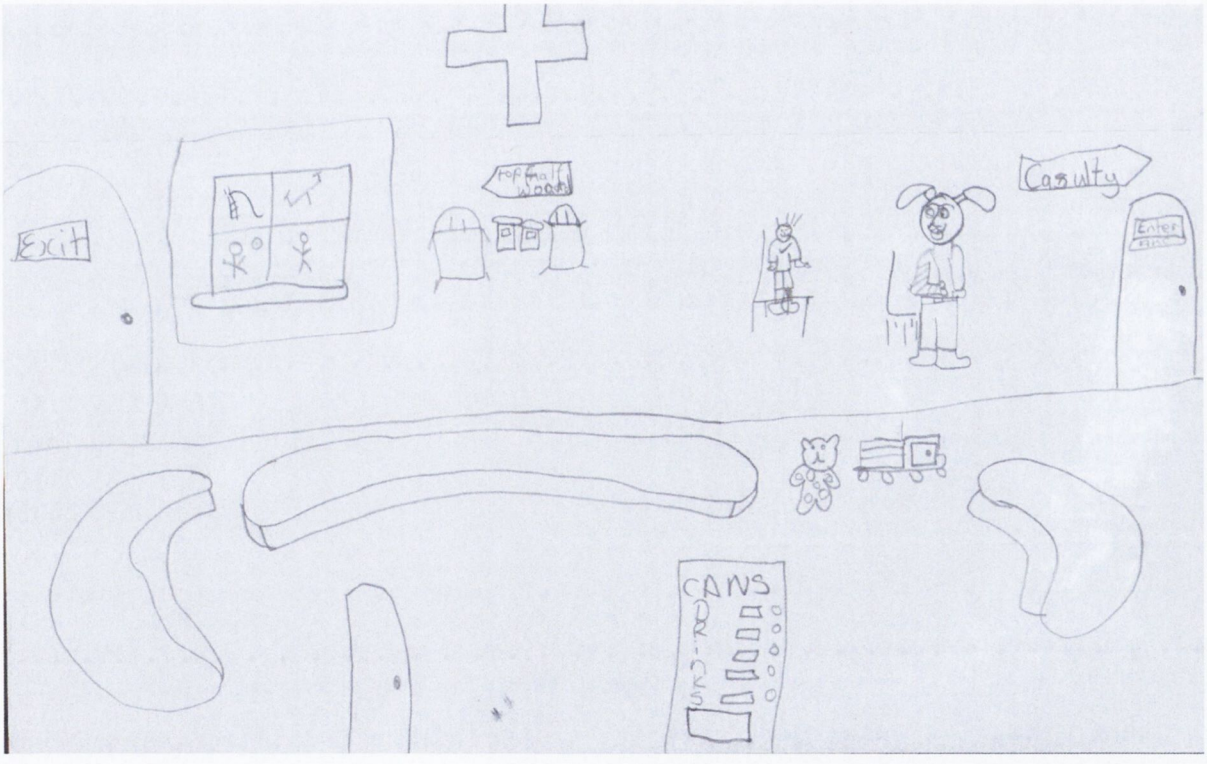
Next to this mission statement is a framed copy of the hospital visiting policy, which endorses open family visiting, as illustrated in the extract below.

> "The philosophy of the [name of hospital] is that every child while in hospital should have the unbroken support of his/her parent(s)/guardians. This is essential in order to maintain a family centred environment and to encourage parents to actively participate in care. The [name of hospital] operates a flexible visiting policy" (Extract from the hospital visiting policy).

This certainly is a far cry from the days of restricted parental access (see Section 2.1). Yet, the *rules* displayed in laminated signs in the hallway, suggests families are *guests* in this hospital setting; with acceptable and unacceptable behaviours highlighted. For instance, the laminated signs inform visitors to switch off mobile phones, not to smoke and to behave appropriately as a guest in this hospital.

At the opposite end of the hospital is the Emergency department. Through her drawing, displayed below, Rosie depicts her vision of the Emergency Department.

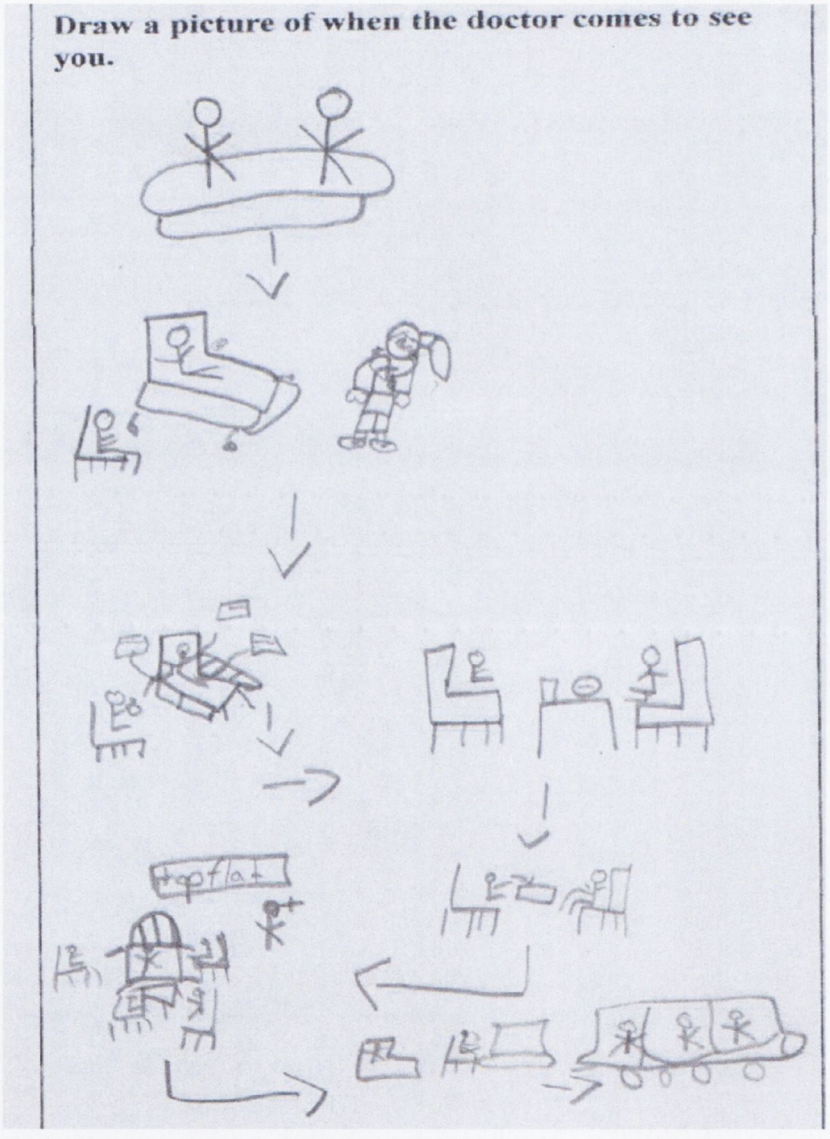
**Drawing 1: Rosie 11 years: Entering the KidZ Hospital (February 2005)**




As Rosie drew her picture, she spoke about a boy, with a broken leg, and a girl, with a broken arm, (shown on the upper right section of drawing 1 above) coming to the Emergency Department. On the upper left side of her drawing Rosie drew a window and relayed the following to me.

> Rosie told me that the boy and girl in her drawing could see outside…they [boy and girl] could see other kids playing and they [boy and girl] couldn't play now with their broken arm and leg. She said they [boy and girl] might have to go to (name of ward). (Field Notes: Informal Conversation: Rosie 11 years: February 2005)

In the bottom half of her drawing, Rosie drew the waiting area in the Emergency Department with big round seats. In this waiting area, Rosie mentioned and drew (as seen in drawing 1 above) some teddies and small trucks that are available and suitable for young children,[152] awaiting treatment in the Department.




While drawing another picture Rosie told her story about her journey through the Emergency Department to the children's ward (see drawing 2).

**Drawing 2: Rosie 11 years: Journey to the children's ward (February 2005)**

[152] Children in Kilkelly and Donnelly's (2006) study reported similar issues in relation to waiting areas catering for younger as opposed to older children.

> Rosie informed me that she had asthma, which she said was *"it's when you can't run very far...you get out of breath"*. She said she was in the waiting area but because she was getting wheezy, they [staff] brought her in straight away. Doctor (first name) examined her. This is a stethoscope she said as she drew it around the doctor's neck. The doctor had used it to check her chest, her breathing. Rosie pointed to herself in the bed and her mam in the chair next to her bed. Next Rosie pointed to herself again and stated *"this is me again ... getting all these things"* (pointing to the IV pump, IV fluids and oxygen). She told me she *"got eight fizzy masks*[153] *[nebuliser]"...*and they [nebuliser] *"just get hot"*. Rosie pointed to the side on the bed in her drawing and then pointed to the side on her own bed saying "like this here" (pointing to the bed side rail). The side rail was up because she was going to sleep she told me. Then next here Rosie stated I'm having breakfast sitting out in a chair. She said she had toast. Then she was colouring. After that she stated that's he came here to this ward [name of ward]. On the ward she pointed that she was in bed and next to her was her mam. Her dad and sisters came to visit but they had now gone home as illustrated in the drawing above, but her mam stayed with her. (Field Notes: Informal Conversation: Rosie 11 years: February 2005)

### 5.2. Barda Linbh

The children's ward where the fieldwork for this study took place was located on the second floor. To reach this ward daily, during the four-month period of data collection, I climbed the main hospital staircase despite the availability of a lift, an inviting alternative to the winding staircase and zillion steps. Painted on the walls outside the lift, at different levels were the colourful and happy faces of *tiger, piglet* and *minnie mouse.*[154] Awaiting collection, large clear and yellow rubbish bags lay against the wall, next to the lift.

Two big brown doors, each with a tiny window to peep through, manned the entrance to Barda Linbh. A magnetic locking system, operated by a button mounted *high up* on the wall next to the door, controlled the door opening. A laminated sign on the door directed new visitors to this door release button. Stuck on one of the doors was a drawing of a puppy with big eyes looking sad and forlorn. Written above and below the puppy was the name of the ward and the picture was signed by the author, a past child patient I imagine,

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[153] This links with a dimension, *being informed*, in the findings which will be reported later in which children talk about health professionals' use of simple terminology to enhance their understanding.

[154] As can be seen from descriptions of the environment much of the décor was geared towards younger children. A number of older children highlighted this to me during interactions with them. This is supported by findings from other studies (Russell-Johnson, 2000; Haines and Johnston, 2001; Sharma and Finlay, 2003; Gibson et al, 2005; Kilkelly and Donnelly, 2006; Coyne et al, 2006; Curtis, James and Birch, 2007). Recently, children and their families, as hospital service users, have been involved in consultations about designs for new children's units (see Boswell et al, 2000; Coad and Coad, 2008).

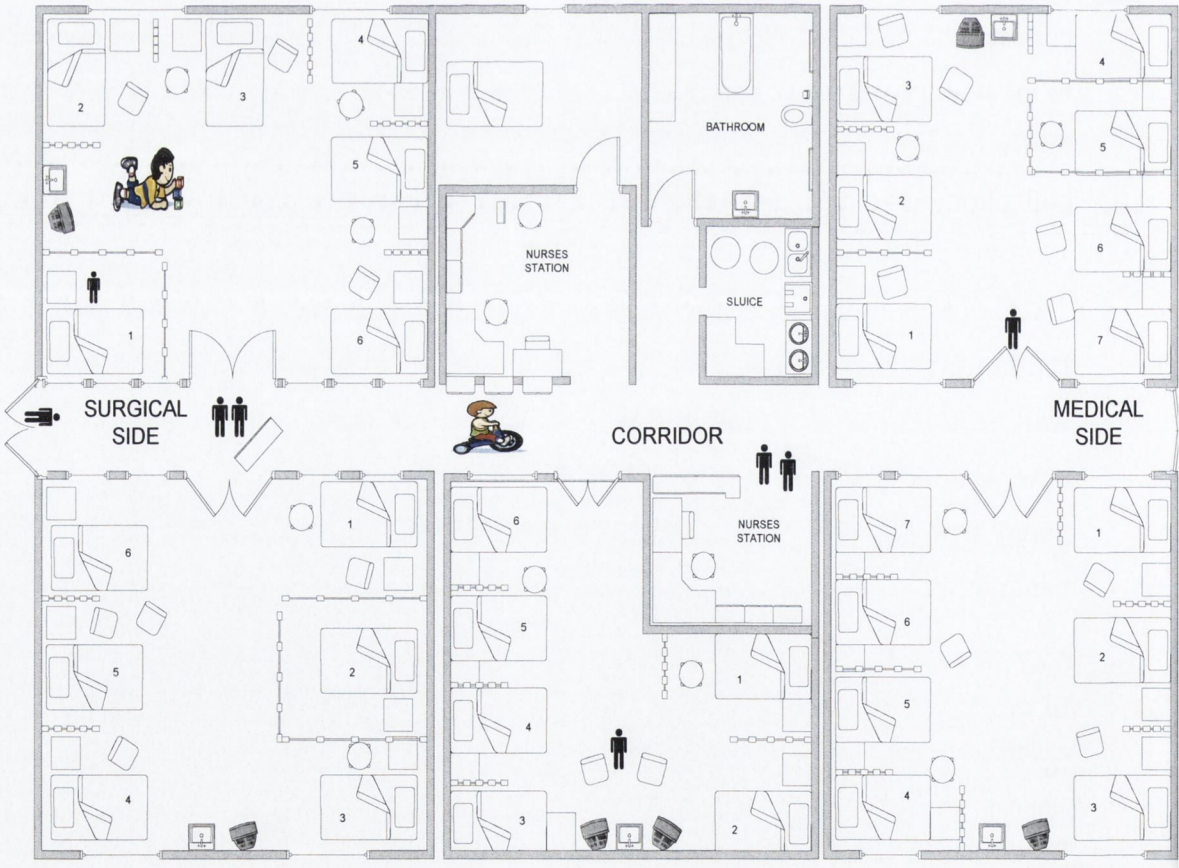
no age was given. Other laminated hospital signs were stuck to the door highlighting health and safety issues, such as - no hot drinks allowed and turn off mobile phones. These written signs were accompanied by visual aids. Next to the door was a framed picture of the hospital visiting policy, similar to that displayed in the hospital's main entrance hall. The philosophy of this children's ward was

> "To provide the highest standard of individualised nursing care to infants and children. We promote holistic, family-centred care by supporting parents or principal carers during their stay in hospital" (Extract from the children's ward philosophy).

### **5.2.1.** Introducing Barda Linbh

At the time of the study, Barda Linbh consisted of a mixture of thirty five beds and/or cots to cater for children aged 6 months to 14 years. The 35 beds and/or cots were sub-divided into five separate bay/ward areas (see Figure 3 below).

**Figure 3: Outline of Barda Linbh**



The distribution of the number of beds and cots in each room changed in line with child admissions, with frequent bed/cot moves witnessed. However, the average number of six to seven beds/cots per room remained relatively constant. The five separate bay/ward areas were further segregated into two specialities, medical and surgical. Seventeen beds/cots were allocated for medical admissions, catering for children with a wide range of specialities, such as general medicine, respiratory, dermatology and neurology. These seventeen beds/cots were subdivided into two rooms of seven beds each and three single rooms (not displayed on Figure 3). The remaining eighteen beds, subdivided into three rooms of six beds each, were allocated for surgical admissions, general, plastic, orthopaedic, ophthalmic and ENT. Depending on bed availability and admissions medical and surgical cases were often mixed together. Thus, as opposed to segregating children together according to their age they were separated according to medical and surgical speciality.

Chloe spoke about how this children's ward differed from an adult hospital. Only the week previous to her admission to Barda Linbh, Chloe had visited her grandmother, who had broken her arm, in an *adult* hospital. Chloe relayed her experience to me.

> Chloe told me that she believed that the adult hospital were her grandmother had been last week was more professional than here, the children's hospital. She went on to say "well like...its professional here [children's ward] as well but different". Chloe informed me that the difference was that it was more organised in the general hospital and not here in the children's ward with the kids. (Field Notes: Informal Conversation: Chloe 16 years: November 2004)

Chloe relayed that she would not necessarily prefer to be in an adult hospital even though she was now 16 years[155] because she would be the youngest there. Orla (10 years) also mentioned being admitted once before to a general regional hospital where she had her own room and television, but said it was not very nice. In their study, Kilkelly and Donnelly (2006) identified that children who were in contact with children's hospitals had more favourable experiences than those in general settings. Chloe went on to

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[155] As mentioned previously (Section 5.1), although the KidZ hospital admits children from birth to 14 years, children on reaching their 14th birthday who were already receiving care at the hospital, often continued their treatment to its completion.

highlight the diverse age ranges of children admitted to Barda Linbh. She relayed that sometimes when the babies were crying she would be thinking *oh stop.* A suggestion put forward by Chloe was that *they should put people the same age together.* Similarly, Brain also complained of the noise of the crying babies and suggested the following to me.

> Brian informed me he felt that all babies should be put together in the same room and they [babies] can then all cry together. He told me that boys the same age and girls the same age should be put together in the same room than they [children] can talk to each other. (Field Notes: Informal Conversation: Brian 10 years: November 2004)

On another occasion, as illustrated in the excerpt below, Maureen mentioned that she was moved to cater for her needs.

> Maureen relayed to me that when she came in first she was in that room over there (looked out window and pointed to room across the corridor). She stated that the nurses introduced her to all the nurses and the other children. She said that she was only in that other room for about ten minutes then the nurses moved her into the room she was in now. Maureen stated that the reason that they moved her was because there were all babies in the first room and the nurses had said that they [nurses] like to keep all the babies together because they are noisy. (Field Notes: Informal Conversation: Maureen 12 years: February 2005)

Barda Linbh was always the height of activity. The words 'mayhem', 'chaos' and 'pandemonium' frequently sprung to mind because while the 35 beds and/or cots were split into five separate ward areas, children were far from segregated, running riot as they moved around; in and out of rooms and traversed the big long corridor. I often thought; how do health professionals keep tabs on their allocated children? Yet, the atmosphere was predominantly friendly. All health professionals appeared to operate with an air of calmness among this frenzy of energetic children. Possibly, it provides a diverse and challenging environment for health professionals to work in.

### **5.2.2.** Physical layout

*The Rooms*

The physical layout of Barda Linbh was easy to understand with undertones of a Nightingale style (a long single open ward plan of anything up to 30 or more beds) which in recent times has transformed into a more contemporary style of bay areas (sub-divisions of 4 or more beds per each bay area) (Patterson and Robertson, 1996). See

Figure 3. One single long corridor ran the length of the ward. Bay areas - patient rooms - faced each other from opposite sides of the corridor. Windows ran the length of the corridor providing a clear view to all patient rooms, advantageous for health professionals, enabling them to continuously and easily observe their child patients.[156] Entry to each room was controlled by double glass doors. Handles for these doors were positioned *high above* any adults head. It was the policy of the ward to keep these doors closed at all times. This did not always happen and when the doors were left open children used the opportunity to 'escape' out to the corridor for some temporary freedom. The general furnishing of the rooms followed the same design, with the majority of the beds/cots positioned parallel to the corridor.

Space was not a thing of abundance but rather in heavy demand. I sat on an armchair between two beds and stretched out my arms. I could easily touch the beds on both sides. Surrounding every bed was a locker (often overflowing with children's soft drinks, toys and sweets), an armchair (for a parent/visitor to sit on), a bed table, numerous pieces of hospital equipment (e.g. infusomats, dynamaps, oxygen, suction machines and oxygen saturation monitors) and an abundance of toys. This severely diminished the availability of any open space, hindering health professionals' ability to get close to children.

All beds/cots looked the same, with starched white hospital sheets and rough blue blankets. Some children broke this dull blue monotony and made the environment more personal by bringing in their own soft quilts and pillows with bright colourful coverings.[157] Around every bed was a curtain rail upon which colourful curtains hung; downed with pictures of trains, cars, monkeys, giraffes, elephants and other animals.[158] The pictures were on the outside of the curtain for people on the outside to see, not the

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[156] The description of the physical ward layout, that is the segregation of the ward areas and bed spaces, the big long corridor and the numerous windows, raises images of Foucault's (1991) discussion of Bentham's *panopticon*, an example of disciplinary power at work allowing for constant surveillance. Similarities between this ward description and that of an adolescent ward described by Hutton (2008) are evident. The overall ward space is laid out for the work of health professionals, providing them with clear visual access to their patients.

[157] This equates with findings from Gibson et al's (2005) and Hutton's (2008) studies whereby adolescence sought to produce their own space when in hospital.

[158] All geared towards younger children, see comments in footnote number 154.

child within. One young girl put her curtain rail to good use as a display for all her Get Well Cards.

At the far end of every room, there are two big long windows. These provide a glimpse of the outside world. The view from one side was of residential flats and cranes from nearby building sites and dirty roofs tops on the other side. At Christmas time, children often pointed to the Christmas lights on the cranes. The hustle and bustle of the street below could be heard. Children often peered out the window in search of their parent's car. In the centre, between the two windows, was a sink with a white tiled splash back. Hand towels, hand wash, disinfectant and boxes of gloves could all be found here. More written and visual laminated signs; do not drink the water and wash your hands were on view here. Mounted on the wall high above the sink was the all important combined television-video unit. Some rooms even had two televisions side by side. Stacked underneath were a pile of videos.

The walls of the ward were painted a plain cream colour with ceiling covings of either boats, aeroplanes, trains or a tea party.[159] Some walls were decorated with painted pictures of childhood characters from different eras, such as, *Pokeman*, *Winnie the Pooh*, *Barney*, *Minnie and Mickey Mouse*, essentially suitable to grasp the interest of younger children. In one of the single cubicles, the windows were covered with colourful pictures, of farm animals, to prevent anyone from seeing into the neighbouring cubicle. One day, while I was chatting with Freddie (10 years) I passed a comment saying *isn't that very colourful and nice, a good idea* [referring to a window which was camouflaged with a farm animal picture]. Freddie's response was *not for me I'm not really into little piggies...if it was football now?* Perhaps, this was one explanation for why children often ascribed their own decors to the walls, for example, boys, and indeed some girls, liked to stick pictures, cut from magazines, of different players from their favourite premiership football team on the walls above their beds. This often created a topic for much banter between children themselves and children and staff. The wards interior decoration often

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[159] Once again geared to the younger child and this further illustrated in the section that follows.

changed according to seasonal events. It was predominantly the play assistants and specialists who engaged with children in decorating the ward environment according to different themes. For example, Halloween decorations in October and in February the windows along the corridor were covered with love hearts and red fancy signs reading *I love you* in preparation for Valentines Day. Various drawings created by children themselves were also often on display.

*The Corridor*

One big long corridor ran the length of the children's ward. The hub of the activity always appeared to take place here. It was definitely the place where one could always find someone. As previously mentioned, windows ran the length of either side of the corridor providing a clear view into all the patient rooms. A ledge extended along the bottom of the windows looking into each room. A variety of items often resided on the ledge top, such as, daily change book, nursing notes, medical charts, oxygen saturation monitors, toys, colouring books, shelving system for forms (referrals, bloods and urine), numerous bottles of sprays for removing adhesive plasters, a box of tops for the genius thermometer and a selection of unused tapes and bandages. Underneath the ledge on one side of the corridor were locked presses, which contained a variety of children's toys and games (key held by play assistant). The area underneath the ledge on one side of the corridor did not have presses but provided storage space for some equipment, for example, wheelchairs, a fold-up mattress (for parents), drug trolley, oxygen saturation monitors, suction machines and a rolling board for lifting and moving child patients. As I maneuvered along the corridor, I noticed some displays along the walls. For example, a laminated sign displayed normal peak flow values, a framed picture of the hospital visiting policy and the hospitals mission statement, a height chart in the style of a giraffe, a holder mounted on the wall for aprons and an antiseptic hand wipe solution, an education notice board for student nurses and a selection of books for children. I pass the entry to the bathroom, narrowed by the presence of linen skips. Further, down to my left, the cardiac arrest trolley was stacked high with heaps of Ambu bags and masks of all different sizes, reflecting diverse child patient sizes.

*The Nurses' Station*

The ward had two tiny cramped nurses stations, centrally located, one either side of corridor, with open access; there was no door. The nurses' stations comprised of a number of colourful presses - red, yellow and blue, as was the main desk area. Despite the small size, they were pretty standard nurses' stations, housing the telephones, computer and an array of health professional educational material. A white board recorded bed numbers, children's names, diagnosis and any other specific instructions deemed important to know about specific child patients. A clock on the wall chimed *moo cow.* There were some framed photographs on top of one of the presses, a photograph of a child, a previous patient perhaps. A plaque stated:

> "To all the staff of (name of ward) for the love and care received by (name child), above and beyond the call of duty we will be eternally grateful (names & family)."

Health professionals came to the nurses' station to write notes, to use the telephone or computer and the nursing handover took place here. It was a rare occasion to see a child visit the nurses' station. Some of the regular hospitalised children (attendees) would enter to chat to the staff nurses', make phone calls (home) and receive their intravenous antibiotics.

### **5.2.3.** Patient turnover

Barda Linbh treats in excess of two thousand, one hundred and fifty children per annum. Per month, the total average number of child admissions to Barda Linbh ranges from one hundred and fifty to two hundred and ten, with slightly more children admitted for surgical reasons as opposed to medical (Table 2). Half of these children fall into the 0-5 year age bracket.

**Table 2: Average Admissions to Barda Linbh**

| **Admissions** | **Per Annum** | **Per Month** |
|---|---|---|
| Medical | 850 | 70-90 |
| Surgical | 1300 | 80-120 |
| Total | 2150 | 150-210 |

The average length of the child patients stay ranges from 3-5 days, with no major difference between medical and surgical patients. Children are admitted medically both electively through the admission office and as emergency through the Emergency Department. Routine surgery takes place in the operating theatres Monday to Friday between 08.00 and 17.00 hours. Outside of these routine surgical hours, emergency surgery often takes place. If admitted electively for surgery, children arrive to the ward the night before their surgery and are discharged the day following their operation.

### 5.2.4. Multidisciplinary team

In Barda Linbh, a multidisciplinary team of nurses, doctors and allied health professionals strive to provide the highest quality of care for children with various acute and chronic medical and surgical health problems. Table 3 provides a breakdown of nursing and medical staff of Barda Linbh, at the time of the study. Other personnel who had contact with the children on Barda Linbh, included, physiotherapists, radiographers, dieticians, ward attendants, domestic staff, schoolteachers, play specialists/assistants and a number of different clinical nurse specialists.

**Table 3: Nursing and Medical Staff of Barda Linbh**

| Medical Speciality | Surgical Speciality |
|---|---|
| Clinical Nurse Manager II (x 1) | Clinical Nurse Manager II (x 1) |
| Clinical Nurse Manager I (x 1) | Clinical Nurse Manager I (x 1) |
| Senior Staff Nurses[160] (x 7-8) | Senior Staff Nurses (x 7-8) |
| Junior Staff Nurses (x 7-8) | Junior Staff Nurses (x 7-8) |
| Post Registration Student Nurses[161] (x 5-6) | Post Registration Student Nurses (x 5-6) |
| Undergraduate Student Nurses[162] (x 2-3) | Undergraduate Student Nurses (x 2-3) |
| Consultant Doctors[163] | Consultant Doctors |
| Non Consultant Hospital Doctors[164]<br>Registrars<br>Senior House Officers | Non Consultant Hospital Doctors<br>Registrars<br>Senior House Officers |

[160] There were approximately 15-16 whole time equivalent staff nurses working in each division, medical and surgical. On average half of these staff nurses were classified as junior and half as senior.
[161] Post-registration (non-supernumery) students were completing a Higher Diploma in Children's Nursing.
[162] Undergraduate (supernumery) students were undertaking a BSc (General) Nursing.
[163] A vast array of Consultant doctors (20-30) with expertise in various medical and surgical areas existed.

### 5.2.5. System of care

Health professionals worked on a shift basis. During my period of fieldwork, I witnessed a change in shift patterns from eight to twelve hourly shifts. Child participants themselves noted these shift patterns. For instance, Annette (8 years) mentioned having different nurses caring for her everyday.[165] In the extract below, Mike described his view of how nurses' changed according to shifts. This conversation with Mike took place before the change to twelve hourly shift patterns.

> Mike informed me that the nurses change frequently. He stated that you would have some nurses for a few days then they [nurses] would change as they [nurses] would have days off. He stated that the nurses seem to get a lot of time off, like every few weeks they [nurses] get a week off he said, however he went on to say that they [nurses] need it [week off] because it's [nursing] a hard job. (Field Notes: Informal conversation: Mike 12 years: November 2004)

Similarly, Maureen expressed similar views, outlining the different day and night shifts, as illustrated in the excerpt below.

> Maureen relayed that she would have the same nurses some days looking after her because some on days and some on nights. She stated she had nurse [name] everyday but not today because she was sick and at night she had [name of nurse] one night just, then she had someone else. (Field Notes: Informal conversation: Maureen 12 years: February 2005)

The total quota of nursing staff and skill mix per each working shift for both the medical and surgical division of Barda Linbh is outlined in Table 4.

**Table 4: Nursing Staff Complement and Skill Mix per Working Shift**

| Medical Speciality | Surgical Speciality |
|---|---|
| Clinical Nurse Manager II (x 1) | Clinical Nurse Manager II (x 1) |
| Registered staff nurses[166] (x 3)<br>Post-registration student nurses (x 2) | Registered staff nurses (x 3)<br>Post-registration student nurses (x 2) |
| Total: 5 nursing staff[167] per shift | Total: 5 nursing staff per shift |

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[164] Non Consultant Hospital Doctors, namely Senior House Officers and Registrars, rotated on a six-monthly to yearly basis. They may not have previously worked with sick children on their first encounter to the KidZ hospital. There were no doctors on internship working in the children's hospital.

[165] The discontinuity of nursing staff has previously been reported as hindering the development of a child-health professional relationship (Coyne and Conlon, 2007) and influencing the level of children's involvement in consultation (Coyne et al, 2006).

[166] One of the staff members could be the Clinical Nurse Manager I

[167] On occasions it was two registered staff nurses and three post-registration nursing students.

A staff nurse was *in charge* for the shift. This meant that he/she would not be allocated a specific patient caseload but would *float* or be *on the floor.* The remaining staff nurses and post-registration student nurses would be assigned to various patient rooms (room allocation) which comprised of six to seven patient beds/cots per room. This was observed by Maureen.

> Maureen informed me that there were always nurses around. There was one always here around this room she said and over there see that room. (Field Notes: Informal conversation: Maureen 12 years: February 2005)

### 5.3. A Typical Day on Barda Linbh

*It is 07.45 hours!*

All feels calm. It is peaceful. There is little movement. The main ward lights are out. Most children are sleeping. Some parents' sit on chairs next to their children's beds looking tired and uncomfortable. Other parents are squeezed in beside their children in bed. Some beds have *colourful* curtains pulled around them obscuring my and others view.[168] The doors to some rooms are closed. One or two children wander momentarily out on the corridor with their father and mother following to bring them back to their rooms. One father is walking the corridor with his young child on his hip.

It is not completely silent. The sound of a noisy old suction machine could be heard coming from one room and the phones were ringing on the corridor. A few young children were crying and coughing. I recognised the sound of nebulisers. I felt a cold wintry feeling. The nurses are gathered in the nurses' station. The muffled sound of their voices is all that can be heard as they hand over their report. Everyone sits around together some on ordinary *adult* chairs, others on small *child* chairs. Night nurses look tired as they prepare to head home. Day nurses listen attentively to the stories the night staff tell mapping what lies ahead for them today. Brief periods of social chit-chat took place between day and night nurses as they change over. The day nurses for the surgical

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[168] Perhaps, the drawn curtains suggest an avoidance of surveillance, highlighting the need for privacy which has been extensively reported in a number of previous studies (Battrick and Glasper, 2004; Gibson et al, 2005; Curtis, James and Birch, 2007; Coyne and Conlon, 2007; Hutton, 2008). Privacy as a core concept warrants further research, especially in relation to the care of children in hospital settings.

patients today consisted of a CNM (dressed in a light blue top and navy trousers), three staff nurses (dressed in a white top and navy trousers), a student nurse [post graduate] and one agency staff nurse. There were also two undergraduate student nurses who were supernumerary to the ward team. At the end of report, room allocations take place. One nurse [staff or student] is allocated to each room. Today, two staff nurses are in charge *on the floor.*

Following handover, nursing staff education sessions take place in the nurses' station. Today a video is shown. A mother comes out from one of the rooms to the corridor looking for medicines for her child. Another mother follows suit, seeking a drink for her child. Their requests are attended to by the Clinical Nurse Manager (CNM), who mans the corridor as the education session takes place. A doctor [surgical registrar] arrives to review Mary (8 years). The doctor speaks to the CNM on the corridor, at the window ledge, outside Mary's room. He states *she [girl] is for an ultrasound tomorrow; continue the antibiotics.* The doctor does not go in to review Mary. Mary is still asleep.

*It is now 08.30 hours!*

The main ward lights are turned on. Suddenly the day begins. The education session has finished. Nurses leave the nurses station, pouring out on to the corridor and wander into their allocated rooms. The general routine of the ward is to make the beds and ensure all children have breakfast. The breakfast trolleys arrive, positioned on the corridor outside the rooms, brought by women dressed in pink uniforms; the kitchen staff. For breakfast, there is cereal, toast and juice. Ward attendants help staff and student nurses distribute breakfasts to the children. The next encounter between Mike and an undergraduate nursing student is representative of the usual scenario.

> An undergraduate student nurse entered the room and approached Mike.
> Student nurse to Mike: Mike what do you want for breakfast?
> Mike: Two weetabix
> The student nurse left the room and went to the trolley out on the corridor to get Mike's breakfast request.
> (Field Notes: Observation: Mike 12 years: November 2004)

Parents and some children appear out onto the corridor looking at the breakfast trolley to see what the options are, as illustrated in the extract below.

> Two children [a girl and boy aged 7 and 8 years respectively] appeared out onto the corridor and peered at the breakfast trolley. A staff nurse arrived saying "now breakfast, you must be (name of boy), what do you want?" The boy replied "*frosties*". The staff nurse handed the boy his bowl of cereal and said "spoon or finger" (laughing). The boy smiled and replied "*spoon*".[169] (Field Notes: Observation: February 2005)

Simultaneous to when children are having breakfast, bed making begins. A member of the domestic staff (dressed in a blue uniform) washes the floors. One of the surgical rooms was in isolation.[170] I was informed by a ward attendant (dressed in yellow top with navy trousers) to wear an apron if entering the room. The heat overwhelms me; my mouth is already dry and I am only on the ward half an hour. Mark (6 years) is sitting on his bed. The CNM asks him to sit out of bed for her. She lets down the bedside and repeats w*ill you sit over here on this chair for me while we make your bed?* He does so. The CNM is at the side of bed next to where Mark is sitting. A staff nurse is on the other side. The CNM pumps up the bed to elevate it. Mark asks; w*hy are you putting up the bed?*[171] The CNM replies *so we won't have to bend down while we are making the bed.* The CNM leans over and bends down towards Mark. She looks towards him and asks *is Santa going to come?* Mark replies *yes.*[172] The CNM asks, h*ave you written your letter yet*? *No not yet* replies Mark. The CNM resumes making the bed and once the bed is made she lifts Mark back onto the bed, puts up the bedsides and moves on to make the next bed.

Across the way in another surgical room a staff nurse says to Jodie (9 years) *will you sit out for me?*[173] Jodie nonverbally agrees with a head nod and gets up out of bed to sit in the chair. No further conversation takes place with Jodie. The nurses chat among themselves while making the bed. The televisions mounted *high up* on the wall in the middle the room is already switched on. It is a rare occasion that televisions are switched

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[169] This represents humour which will be referred to later in the findings (see *"humanistic qualities").*
[170] Isolation refers to a measure to minimise the risk of the spread of infection
[171] This illustrates the child asking questions and links with findings, which I will discuss later in relation to children stating that they were told because they asked.
[172] Does this illustrate a form of tokenistic involvement through social chitchat?
[173] Task focused care is demonstrated here.

off. Cartoons are showing.[174] For some children this is the start of a day long viewing. Sometimes there is a bit of banter or more precisely *fighting* about the television and what to watch; more often than not it is boys and girls arguing over programmes they want to watch.

*It is now about 09.15 hours!*

Medical and surgical doctors start to arrive. Doctors do not wear the traditional *white coats* but rather dress casually in ordinary clothes, identifiable by the stethoscope hanging around their neck.[175] This was highlighted by Sean (10 years) when he was drawing a picture of when the doctor came to visit him (see drawing 6 on page 241). Sean drew a picture of the doctor wearing ordinary clothes. Then, Sean asked me *will I draw [doctor] him with a big white coat?* I asked Sean, *do the doctors in this children's hospital wear white coats?* Sean replied *no, on TV*. So, Sean did not draw the doctor with a big white coat but continued to draw a stethoscope around the doctor's neck. Surgical doctors tend to wear scrubs (traditional attire of operating theatre staff). This was highlighted by Gary (11 years) who talked about the doctor wearing *blue clothes.*

All children's medical notes are stored in pigeonholes along the corridor outside the nurses' stations. Doctors gather along here; in the nurses' stations or stand along the corridor at the window ledges outside the patient's rooms. From here the doctors get a clear vision of the children and have a worktop from which to review medical notes. This stimulates thoughts of Foucault's (1991) surveillance strategies. Peering through a window into one room I see a consultant, dressed in a suit, on his knees on the floor. He is following a young boy, aged 6 years, in an attempt to listen to his chest. The boy's mother watches closely from where she is sitting on her son's bed. Meanwhile out on the corridor a CNM is carrying a young child on her hip while simultaneously attending to a

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[174] This links with the busyness of children, as will be further demonstrated within the findings chapter.
[175] Representing a capillary form of power (Foucault, 1991)

consultant ward round. Two children (aged 6 and 8 years) fly around the doctors on bikes. This highlights the active busyness[176] of children despite their *sick role.*

In the drawing displayed below, Rosie (11 years) drew a picture about what was happening in her room on Barda Linbh[177]

**Drawing 3: Rosie 11 years: A day in a life of a hospital bed (February 2005)**




[176] Children in Coyne and Conlon's (2007) study also referred the busy ward environment and throughput of 'ward traffic'. The active busyness of the children and health professionals will be demonstrated later as it emerged as a key dimension of the findings of this study.

[177] Some important things Rosie described about her drawing were, the presence of her mother sitting in a chair next to her bed, the presence of Kelly (13 years) in the next bed, a doctor standing at the end of Kelly's bed leaning on a bed table with a medical chart open in front of him, a nurse outside the room at the window on a computer, a nurse sitting on a chair in the room writing, a wall with some posters and pictures (I noted one of the posters on the wall in the room was the charter for children's rights in hospital from the voluntary organisation Children in Hospital Ireland), the television and finally other equipment such as the oxygen points above her locker and the sink in the middle of the room in front of her.

*It is now 09.20 hours!*

Two staff nurses are attending to the medication round. This must be completed before the children head off to the playroom and school. The positioning of the medication trolley depends on who is undertaking the medication round. Sometimes the trolley is wheeled into each individual room, at other times it is positioned just outside the room on the corridor. At this time routine questions posed to children are; *are you sore? Will I get you some calpol? Do you want tablets or liquid?* This is followed by; *can I just check your name band.* Then *will you take this for me?* Or, just simply *take this.*[178] For example, Tom (13 years) mentioned his pain being still there, after his operation, especially when he moved. He found taking tablets hard. At first he was given some liquid which was *rotten.* He was not able to take it, so he was given tablets. Although the tablets were difficult to take they were better than the liquid because Tom relayed that he could break up the tablets to make them easier to swallow. Siobhan talked about getting pink tablets which dissolved in water, as illustrated in the extract below.

> Siobhan relayed to me that she don't know the name of the tablets she was getting. She said that sometimes she gets them [tablets] at home at well when she has a cough. She informed me that the dissolve ones [tablets] are easier to take but they [dissolve tablets] don't taste very nice so she dissolves them in 7up to get rid of the rotten taste. (Field Notes: Informal conversation: Siobhan 10 years: October 2004)

Some children also talked about getting their intravenous medication, as illustrated in the extract below.

> Deirdre informed me that the nurses come and first give some water into "this" (pointed to her intravenous cannula) and she said the nurses give some medicine and then more water before they are finished. She stated that they [nurses] do all this, not with a needle but something like a needle without the sharp bit at end. Deirdre told me it was to get rid of the germs in her throat. (Field Notes: Informal Conversation: Deirdre 12 years: October 2004)

Also at this time, staff nurses and student nurses begin the *obs* [observations].[179] The children refer to these *obs* as the nurses' *checks*. Nurses are frequently observed saying

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[178] Here is illustrated the predominant use of closed questions by health professionals in their interactions with children and limited provision of information, which will be further illuminated within the findings chapter.

[179] These examples highlight the task focused nature of nurses' observations, in addition to illuminating that when performing these observations nurses often provided limited information to children about what they were doing. This will be further illustrated within the findings chapter.

such things as; *I'll just check these* [arriving to child's bed with portable dynamap and pulse oximetry machine], *can I check your temperature, let me see how hot you are?* and *put this on your arm* (placing tympanic thermometer in child's ear then placing blood pressure cuff on the child's arm), *I'll just take your arm here* (placing blood pressure cuff on the child's arm), *just put this [oxygen saturation probe] on your finger* and when completed on leaving stating, *now that's you finished.* These observations are recorded routinely and ritually, as illustrated in the next extract.

> The post registration student nurse asked the undergraduate student nurse to check Chloe's (16 years) *obs*. The undergraduate student went to Chloe but returned saying "she's [Chloe] asleep, will I wake her to do them [observations]". The post registration student relied *yes, we're behind they're 10 o'clock observations.* (Field Notes: Observation: November 2004)

Brain also talked about the nurses routinely checking his pulse every four hours.

> Brian said to me *that's for that* [points to monitor] *shows pulse and all.* He then stated that the nurses check it every four hours or so. (Field Notes: Informal Conversation: Brain 10 years: November 2004)

Soon, the schoolteacher and play assistant arrive. They gather together all the children that can go to school or to the playroom. The school and playroom are not attached to the ward area but separate, located a short distance away in a communal area, open to all ward areas. I pay a visit to the playroom and school, as outlined in my field note extracts below.

> Outside the door to the playroom are fire action notices, visitors notice for inappropriate behaviour, health and safety notices, the charter for sick children in hospital and a poster from Children in Hospital Ireland seeking volunteers to help with the hospital play scheme. The playroom door itself is white but painted blue with colourful fish and a notice stuck to the door displays opening times (10.00-12.30 & 14.00-16.30 Monday to Friday). Right of the door is a poster with photographs of hospital staff dressed in theatre scrubs with red clown noses performing a play for previously hospitalised children. The handle to access the playroom is high up. I'm in the playroom, the children are at ease chatting and playing as if they were not in hospital. The playroom is divided into two sections. One section had a pool table, a darts board, play station, two round low tables and small low chairs around the tables. There is also a big rocking horse and table football. In the other section there are shelves full of games, toys, videos, a small slide and some beanbags. There is always one play staff member in each section. Play staff range from volunteers to play specialist. On entering the playroom all children had to introduce themselves and say what ward they were from. I noted some children had stickers on them with their names, some stated visitors and some indicated that children were fasting. Although the playroom is open to all child patients, children over four years are encouraged to go to school and can attend the

> playroom once school finishes at three o'clock. The play department also provides a preadmission club, held once a month for hospital elective admissions.
>
> The hospital school is situated next to the playroom through what I call a tunnel, a narrow passageway wide enough for just one person to pass through at any one time. The Department of Education and Science fund the hospital school, which comes under the rubric of special education. Three teachers and ward assistants staff it. It is divided into classroom and ward teaching for those children unable to get out of bed or leave the ward area. All children over the age of four years are welcome to attend. Along the corridor outside the school the children's creative schoolwork, current affairs, the schools mission statement, opening hours and a poster on the convention of the rights of the child is displayed. Children engage in a wide variety of activities in the school, art workshops, music workshops, textbooks/library books, computers, quizzes, worksheets. (Field Notes: A visit to the playroom and school: October 2004)

When children talk about what was good about the hospital, the majority mention playing and school.[180] Jodie (9 years) described hospital as *boring and lonesome but good at times*, equating these good times to play and school. Furthermore, when asked what they did all day in hospital children consistently mentioned attending the playroom and school. Yvonne (13 years) talked about going to the school to do some pottery. Interestingly, Brian (10 years) relayed that he could not go to the playroom until after three o'clock in the afternoon because they had a crèche there. This was something I also encountered when I accompanied a mother and her son (8 years) to the playroom one mid-morning. When we arrive at the playroom, one of the play assistant's asked the mother how old her son was. The mother responded, 8 years. The play assistant reiterated what Brian had identified, that only children under 4 years could attend the playroom until school was finished. The play assistant said, *we have to encourage children to go to school, they do arts and crafts there it's not like real school.* Other children mentioned that they had not visited the school or playroom. Annette (8 years) talked about being bored, and fed up, highlighting that the reason she did not get to go the playroom or school was because she came in on Sunday and Monday was a bank holiday, and the playroom was not even open. Tom (13 years) expressed a similar view. During the weekdays, for those children unable to leave the ward area to attend the playroom or school, the play assistant would organise toys and games, and the schoolteacher schoolwork for the children to do on the

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[180] This aspect here in relation to discussion of school and playroom illustrates children's busyness, which emerged as a key dimension and will be further expanded upon within the next findings chapter.

ward. There is play stations, game-boys, board games, playing cards, videos and DVDs, to mention a few. The children liked to be busy otherwise they became bored, as highlighted by Jodie, Annette and Denzel.

*It is now about 11.00 hours!*

I am out on the corridor again, two children, aged 6 and 8 years, are literally flying along on two little bikes. Adults had to move out of their way. My heart was in my mouth as one boy (6 years) was flying towards me. He was quickly stopped in his travels. A ward attendant came after him; she got down on her knees on the floor, faced the boy and called him by name. She said *listen be a bit quieter some babies are asleep.* I then noticed the boy was hand cuffed, with, thank goodness, toy handcuffs. On the other bike, the slightly older boy (8 years) had gone ahead and turned into one of the rooms off the corridor. The younger boy (6 years) followed him in. In here, he stopped at the feet of a ward attendant and looked up in her direction calling her by her first name (the ward attendant was chatting to a staff nurse). The 6-year-old boy kept calling the ward attendant by name until she responded saying *what?* The boy lifted his hands to show her the handcuffs. The ward attendant asked; *who put them on you?* The boy did not stop for long as he was off again. He went straight across the corridor on his bike into the other surgical room. A mum carrying a glass of milk had to do a quick side step to avoid him. A nurse passed him by and seeing the handcuffs stated *I don't think he's supposed to have them on* (smiling), she kept walking. As she passed the second boy (8 years) she paused, stood above him looked down and stated *(name of boy) be careful because if you knock (name of boy 6 years) over or you'll be in trouble.*

*It is now 12.30 hours - lunchtime!*

All children start to arrive back from the playroom and school. Like breakfast time, the food trolleys arrive. They are positioned outside the rooms on the corridor. Once again, ward attendants, staff and student nurses all help to distribute dinner to the children. Referring to the girls in yellow (ward attendants), Brian (10 years) relayed; *they help with*

*the dinners and all.* Consistently, children talked about not liking the hospital food.[181] Rosie (11 years) stated she was starving because she did not eat breakfast. She does not like cereals and the toast was cold. She went on to say they always seem to get mashed potato as well and she hated mash potato. Meal times were often a battle, with health professionals constantly bargaining with the children in an attempt to get them to eat something, anything at all, as illustrated in the extracts below.

> Jodie was sitting on her bed with a bed table in front of her, on which was her dinner, which was a bowl of noodles and glass of milk.
> Veronica: Hi there, you're having dinner
> Jodie: (smiled) Ya, don't want it
> A post-registration student nurse approached the bed.
> Student nurse (as if speaking to me): I think she wants to stay here…she can go home if she eats.
> I sat on the end of Jodie's bed
> Jodie: I feel sick when I eat
> A staff nurse came over to Jodie's bed.
> Staff nurse: Now will you eat for veronica
> Jodie: (smiled and nodded head indicating no)
> Staff nurse (as if speaking to me): She's drinking not eating
> Staff nurse to Jodie: Are you sore? Is your tummy sore?
> Jodie: No I feel sick when I eat…drinking is okay
> A second post-registration student nurse came in and approached Jodie
> Student nurse: What did the doctor say to you this morning? (leaned over)
> Jodie: I can go home if I eat
> Student Nurse: So what do you have to do?
> Jodie: Eat…..I can't
> Student Nurse: Will I go see if there's ice cream in the fridge?
> Jodie: No
> Student Nurse: Think of something you would like…..anything you want....well there is another pot noodle in the kitchen, so maybe later you'll feel like that and she left.
> (Field Notes: Observation: Jodie 9 years: November 2004)

Following the above encounter, Jodie pushes her food away. She suggested we go for a walk along the corridor. As we walked Jodie pointed out a bottle of spray that the doctor had used on her dressing and told me it was just water. I inquired had Jodie been to the playroom that morning, she stated that she had asked to go but the doctor said no she was not allowed to, not until she eats something. As we walked further along the corridor, a staff and a student nurse approached us.

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[181] Children's dislike for hospital food is not unique to this study and has been frequently documented elsewhere (Heary, 2001; Curtis et al, 2004; Gibson et al, 2005; Clift, Dampier and Timmons, 2007). A specific exploration of *food* for hospitalised children warrants further investigation.

Staff nurse to Jodie: Did you eat anything?
Jodie: No
Staff nurse: Will I ring your Mam and ask her to bring you in something from home that you would eat?
Student nurse to staff nurse: But she had pot noodles for lunch, that's what she normally eats at home
Jodie: I'll eat when I go home
Staff nurse: I'm sorry... it doesn't work like that…sorry...you have to eat here!
Jodie: Yesterday ... telling me to drink and not eat and today eat
Student nurse: You know you can go home if you eat…do you not want to go home?
Jodie: I do.....I can't sleep in here
Student nurse: ...and you need your beauty sleep
Jodie: I don't get beauty sleep
Student nurse: Well how come you're so pretty then!
(Field Notes: Observation: Jodie 9 years: November 2004)

Similar to Jodie above, Rachel also mentioned that she was not allowed to go home until she was eating and drinking, but she did not like the food. Interestingly, I recorded the following extract following an interaction between Katie's mother and Rachel.

Katie's mother: You're (Rachel) in a while?
Rachel: Ya the doctor came today and said that he'll do an ultrasound on Friday and if it's okay I can go home…I have to eat and drink.
Katie's mother: Do you like the food in here?
Rachel: Em em…(scrunched up nose)
Katie's mother: It's okay you can say you don't
Rachel: Well not really…….I liked the sausages…my mum clapped 'cause it's the only thing I've eaten since I came in here…….my sister asked me to get some chips for her but when she tasted them…rotten
Katie's mother: Do you like fish fingers…or crispy chicken pieces….ask for them they're nice. You might be better to pretend and like it [food]…just eat it for a day or two to get home then you get your mam's cooking….or are you from Dublin…get your mam to bring in dinner on a plate and they can heat it in the microwave.
Rachel: Em ya …might eat it just to get home.
(Field Notes: Observation: Rachel 9 years: February 2005)

Just as lunch is nearly finishing, two play volunteers (dressed in ordinary clothes with long white aprons, with colourful pictures all over them, covering their clothes) arrive to the ward. The play assistants walk around collecting toys that had been handed out earlier in that morning. First, they check with the children to see that they are finished with the toys, for example, they ask a 6-year-old boy if he is finished with the house, which in fact is a play hospital, he was playing with. As the play assistant gathered the house with its little figures she noted his dinner still sitting on his bed table and looked down at him on

the floor and asked *are you not eating your dinner?....oh come on...you'll be hungry later*, then left.

*It is 13.00 hours!*

It is time for the medication round again. Deirdre talked about getting medication for pain routinely.

> Deirdre relayed to me that the nurses give her "it" [Medicine - Brufen]. She doesn't have to ask for it [medicine] but gets it about every three hours. She stated that she knew this medicine [Brufen] because she was taking this at home before she came in as well, although it was a different colour. (Field Notes: Informal conversation: Deirdre 12 years: October 2004)

Similarly, Emily also talked about getting her medicine a couple of times a day. Emily relayed that her intravenous cannula was for getting her medicine.

> Emily stated that she didn't know what medicine she was getting, the nurses didn't tell her, but she said that she gets it four times a day...two times in the day time and two times at night. She relayed that the nurses woke her up last night to give it to her and she got a fright. She didn't know what was happening. She jumped. (Field Notes: Informal conversation: Emily 7 years: December 2004)

*It is nearly 14.00 hours!*

As it nears two o'clock and lunches finish, the play assistants arrive on the ward again. Once again, it is off to the playroom for the younger and school for the older children. This was something extremely striking about the children's ward; the massive exodus that occurred when all children who were able, unless very sick or bed bound, left the ward to go to the school or playroom. The ward suddenly became calm and quiet. Some children remain on the ward. A staff nurse enters one of the rooms, she does not do or say anything just scans the room and walks out again. A second staff nurse did the same thing a few minutes later. All the children are once again engrossed in a variety of activities.

I noticed Damien (6 years) walking along the corridor with a physiotherapist. Damien was keeping the weight off his sore foot and the physiotherapist was standing at his side. They were stopped in the middle of the corridor. Damien was learning how to use a walking frame to help him keep the weight off his sore foot that was operated on. The physiotherapist was holding a handful of crisps and Damien was eating them from her

hand, Damien's younger brother, who was in visiting, was running out of Damien's room and along the corridor to ensure he also got to eat some of the crisps.

Joanne enters the nurses' station.

> Joanne to staff nurse: Can I ring my granny?
> Staff nurse: Ya
> Joanne sits up on the bench in the nurses' station
> Staff nurse to Joanne: Sit here (pulling over a stool for Joanne to sit on)
> Joanne: What do I have to press (looking at the telephone)
> Staff nurse: Nine, then the number
> Joanne made the phone call and was chatting to her granny, the staff nurse had left the nurses station. A short while later the CNM entered the nurses' station.
> CNM to Joanne: You'll have to finish now, we need the phone.
> (Field Notes: Observation: Joanne 14 years: January 2005)

Throughout the day, a number of children are called for and taken to the operating theatre. In the extract below, on her return, and when she had recovered from her anaesthetic, Chloe relayed what happened when she arrived at the operating theatre.

> Chloe relayed that at first they [staff] had to check her (pointing to her name band). They always have to do that she said. Then they asked questions and both her dad and herself answered them between them. She said they asked about allergies, fasting and the toilet. Then her dad had to get dressed up in a white coat and hat. She had to move from the trolley onto a bed. She told me it would be warm and like a water bed. Chloe stated that when she and her dad went in to the operating room one of the staff told her that she'd tell her everything that was happening and she did. Chloe stated that she told her she was giving the injection and that's all she remembered. (Field Notes: Informal Conversation: Chloe 16 years: November 2004)

A ward attendant approaches Katie (12 years) a regular attendee to the children's ward.

> Did you get your GHD [hair straighter] brought in?
> Katie: Yah
> Ward attendant: As if you need it…..it must be my eyes if that's not straight (looking at Katie's hair)
> Katie wandered out onto the corridor with the ward attendant and stood outside the room at the window ledge chatting with her
> (Field Notes: Observation: Katie 12 years: January 2005)

Paying a regular daily visit the Chaplin manoeuvres her way around the ward. A typical interaction would be that of the next extract displayed below.

> The Chaplin entered the room. She approached Brian's bed. Brian was sitting on his bed with his mother sitting on a chair next to his bed. When Brian's mother saw the Chaplin approach his bed, she went to get up to allow the Chaplin to sit down.

Chaplin to Brian's mother: No... I'll get down here (getting down on her knees and kneeling on the floor facing Brian with Brian's mother at her left side)
Chaplin to Brian: How are you?....you're looking better...your eyes are better, you're getting nearer to the door
Brian: I'm at the starting grid and 50 metres on…the nebuliser is good....it works well…I might be going home this afternoon
Brian's mother: I'm telling him not to get his hopes up, to wait and see what the doctors have to say
Chaplin: Yes, that's right, wait and see
After the Chaplin had left Brian asked his mother: Is she a nun?
Brian's mother: Yes…its good the way she goes around everyday to see all the kids. (Field Notes: Observation: Brain 10 years: November 2004)

Aoife was sitting out in an armchair beside her bed. She was drawing. Her mother was sitting on a chair next to her reading. It is nearly teatime.

Aoife starts to grimace and told her mother she was sore (taking a breath in and holding her side). Aoife's mother went out onto the corridor to seek a nurse and ask for some painkillers for Aoife. Aoife's mother returned to the room and was shortly followed by a staff nurse who brought some calpol
Staff nurse to Aoife: Are you sore?
Aoife: Yes
Aoife's mother: She leaves it too long between taking it (pain medication), she hasn't had any since ten o'clock this morning
Aoife: But I wasn't sore
Aoife's mother: But you shouldn't leave it until you get sore
Staff nurse: I know…well take this [calpol] now it'll help (handing Aoife medication cup)
Aoife takes the medication cup and makes a rotten face by scrunching up her nose
Aoife's mother: She's turning off medicines
(Field Notes: Observation: Aoife 10 years: November 2004)

*It is 16.30 hours!*

Once again, there is a buzz on the ward. The calm and quietness has changed to noise and busyness. The children have returned from the playroom. It is teatime. While the majority of children did not like the hospital food, Aoife stated *I know everybody gives out about it [food] I don't mind it [food]... I like the toast ....its [food] ok for kids.*

A post-registration student nurse arrived saying 'teatime'. She walked over to Aoife and stood in front of her.
Student nurse to Aoife: Will you try something, some…chips…and I think its chicken...not sure... (looking out and pointing to the food trolley on the corridor)
Aoife: Am I allowed to have that [chips and chicken]?
Aoife's mother: Well at lunchtime you could have had a full dinner

The student nurse brought in the tea (chips and chicken). She also brought some ketchup.
Aoife: Can I get ketchup?

> Student nurse: See I know what you like.....what would you like to drink...milk or juice
> Aoife's mother to Aoife: Will you drink some milk?
> Aoife to her mother: Can I get tea?
> Aoife's mother to student nurse: Would it be possible to get some tea to drink
> Student nurse: I'll go check
> (Field Notes: Observation: Aoife 10 years: November 2004)

Following the above interaction Aoife's mother explained to me that the policy on the ward was you were not allowed any hot liquids, even the children themselves, but milky tea was all Aoife liked to drink. A short time later the student nurse did return and Aoife was allowed to have some tea to drink.

*It is about 18.00 hours!*

Although new patients were admitted throughout the day it was more often than not that in the early afternoon or the evening time that new admissions were seen arriving to the ward. A staff nurse entered one of the rooms, in which a new child, his brother and mother had just arrived to the ward. The staff nurse introduced herself to the 'new' child, his mother and brother. Immediately, the boy asked the nurse about going home. The staff nurse replied, *no usually they admit you....keep you in...you won't be in for long though. Now someone else will come to admit you.* A post-registration student nurse arrived to admit the boy. She introduced herself and the other post-registration student nurse in the room *we're the nurses looking after you this evening.* In the extract below, Chloe describes her experience of the admission procedure.

> Chloe told me about when she first came to the children's ward. Chloe stated that when she came to the ward first the staff asked all these questions, about what you eat, they did her weight, asked her date of birth and did she have any children herself (laughing). Chloe stated that she just laughed saying no. She was also asked if she had any body piercing and when she told them about her belly button one she was told that it [belly button ring] would have to come out for her surgery. She stated that she had asked if it [belly button ring] could just be covered but no it had to come out and earrings and all (pointing to ear rings). (Field Notes: Informal Conversation: Chloe 16 years: November 2004)

Whereas, Chloe (above) was admitted electively to the children's ward, in the next extract below, Sean describes his experience of being admitted through the emergency department.

> Sean relayed that he was just admitted this morning with a pain in his stomach. He was sent home from school. His mam thought he didn't look very well so she took him to the local doctor then his [local doctor] had said go to the hospital. He was downstairs in casualty for four hours but he wasn't waiting to be seen. He stated that he was brought in straight away and asked questions by the nurse and then had to fill in a form, then he was brought in to see the doctor, who examined him. Sean relayed that they didn't do any scans or X-Rays the doctors just felt around his tummy. They got him to hop up and down to see if he was sore. They told him he'd probably need to get his appendix out. (Field Notes: Informal Conversation: Sean 10 years: November 2004)

Although visitors trickle in and out of the children's ward throughout the entire day they (visitors) seemed to pour in more in the evening time, parents, grandparents, siblings, aunts, uncles and friends, to mention just a few. Around five or six o'clock there is often a lot of chatter with loads of laughter. Visitors were important to the children. Now that the playroom and school were closed it provided them with vital company. Children often talked about getting cards and presents. While visiting was unrestricted for parents, other visitors had to leave by 19.00 hours.

Children often talked about things that happened late into the night. For example, a number of the children talked about staying up late. Katie (12 years) told me Stewart (13 years) and herself were up chatting until early hours of the morning (half-past two). Similarly, Chloe (16 years) stated that despite the fact that she was the only girl in the room one night she did not care because she had a laugh. Chloe went on to tell me a story about the night before her operation being up late messing in their room, until half-past eleven at night. A nurse had come in a couple of times to tell them [children] to be quite, get into bed and go to sleep. Disappointingly, Chloe said; *when I had come back from theatre they [other children in her room] had all gone home.* Contrastingly, Jodie (9 years) mentioned going to sleep at half past nine because the television was switched off, as illustrated in the following excerpt.

> Jodie told me that she thought she was going to watch Scary Movie 2 last night but the TV was turned off…that was at half nine….so she just went to sleep. (Field Notes: Informal Conversation: Jodie 9 years: November 2004)

However, in the next two excerpts below, Jodie talked about the difficulty she experienced with sleeping.

> Jodie told me today that she hoped she would sleep tonight. She relayed that she had been awake at seven this morning. She stated that she don't know [why], just awake, when she had her operation she was awake at four o'clock she said. (Field Notes: Informal Conversation: Jodie 9 years: November 2004)

> Jodie stated you know what I hate, I can't sleep, I hate that ya wake up in middle of the night....don't know why.....coughing, but I can't cough because it's sore. (Field Notes: Informal Conversation: Jodie 9 years: November 2004)

Other children also mentioned their difficulty in sleeping.

> Katie stated that she didn't sleep at all last night and at three o'clock in the morning she texted [mobile phone] her brother in America. She was still awake at five. The night was going so slow. Then she fell asleep only to be woken this morning by (name of cystic fibrosis nurse specialist). (Field Notes: Informal Conversation: Katie 12 years: January 2005)

Joanne talked about getting her medicine at night.

> Joanne said "see that (pointing to intravenous cannula in arm) I get my medicine at night...that other one (intravenous cannula in hand) is for that (pointing to drip)". (Field Notes: Informal Conversation: Joanne 14 years: January 2005)

Brian also described some reasons why he found it difficult to sleep; it was too bright and noisy.

> Brain stated that .it could be darker; the lights on the corridor are left on all night. He stated that he pulls the curtain around his bed but it [light] still shines in (pulled the curtain beside his bed to show me). Brian also relayed that if the nurses need to do things with other kids in the room (pointing to a child opposite) they [nurses] turn on the light in the room above their [the child's] bed. He stated that it can also be noisy, .the nurses make the most noise and also the babies crying. (Field Notes: Informal Conversation: Brian 10 years: November 2004)

The difficulty children experience with sleeping in hospital is not a novel finding as it has previously been reported in other recent studies exploring children's hospitalisation experiences (Battrick and Glasper, 2004; Curtis, James and Birch, 2007; Coyne and Conlon, 2007). However, there is a lack of more extensive research, which focuses solely on sleep for children in hospital.

### 5.4. Conclusion

An often neglected, yet an extremely important aspect of any research, is to describe the context of where the study took place. Perhaps, the tendency to describe the sample in numerical terms accounts for this overlooked area, dismissing the environmental context.

However, describing the context, site and setting of where the study took place is integral within an ethnographic approach. Thus, this chapter described contextual details of the KidZ hospital and Barda Linbh where this study took place. Additionally, a typical day on the children's ward was outlined, complied from an amalgamation of various modes of data collection, namely my participant observations and the informal conversations (including children's drawings) with children, in addition to supplementary data obtained form key hospital personnel and documentation. This will in some way lend itself to enabling the reader to determine the transferability of the study findings. Furthermore, this chapter helps to set the scene for the next chapter, which will describe and discuss the nature of communication for children admitted to Barda Linbh.

# CHAPTER 6: PRESENTATION OF FINDINGS

## 6.0. Introduction

This purpose of this study was to explore and describe the nature of communication, for children, admitted to a specialist children's hospital. Using an ethnographic approach with various tools of data collection, namely participant observations; informal interviews; draw and write technique; and child appropriate worksheets (stick-a-star quiz); data were compiled over a four month period on one children's ward. Data were then subjected to an intense and lengthy period of analysis (see Section 4.15). In order to stay close to and represent the child's voice, thick descriptions of all modes of data, taken from my ethnographic field notes,[182] will be presented to elucidate the emergent findings. Owing to the multi-methods of data collection, after each data extract, the source of the data (in addition to the child's name, age and date) is made explicit in round brackets, for example, (Field Notes: Informal Conversation: Rebecca 11 years: November 2004). As a tape-recorder was not employed, either during observation of interactions or informal conversations with children, verbatim extracts are not advanced but rather paraphrased translations of what children informed me and of what I observed, all of which I recorded in my ethnographic field notes (see Section 4.13). Fieldnote excerpts presented were chosen, not because they were necessarily 'exotic' illustrations of the data, but because they explicitly portray the argument being made. Although every effort was made to represent all children some key child participants[183] appear more frequently. Data excerpts will be portrayed in ample detail and length in an attempt to preserve the context of the communication. As children's opinions were not restricted to one particular structured mode of data collection their experiences have not been quantified. To maintain confidentiality, all children have been allocated pseudonyms. Reference will be made to pertinent literature throughout, to assist in clarifying and validating results.

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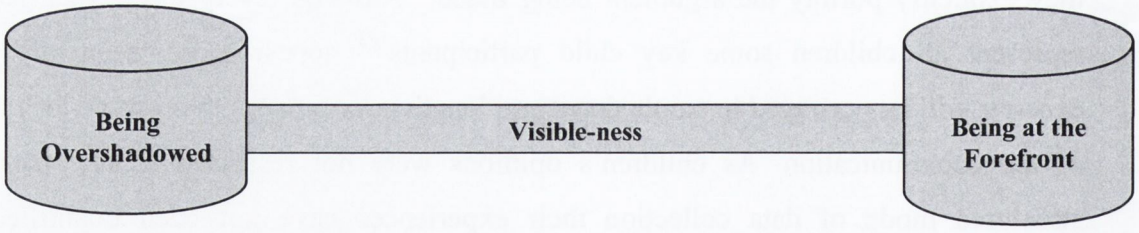
[182] My ethnographic field notes refers to all written details of my observations, my informal conversations with children, some of which incorporated the draw and write technique and stick a star quiz.

[183] In ethnography key informants, or participants as referred to in this study (see footnote 102), were selected based on their role, knowledge, insight and willingness to talk (Baillie, 1995). In this study key child participants tended to be children whom I had most contact with, thus built stronger rapport and those who spoke more freely.

## 6.1. Overview of the Core Construct: *"Visible-ness"*

The construct[184] *"visible-ness"* conceptualises the nature of communication, for children, admitted to a children's ward in a specialist children's hospital. The noun, *"visible-ness"*, is defined as "the quality or fact or degree of being visible" (http://www.thefreedictionary.com/visibleness). In the context of this study, the use of the term *"visible-ness"* goes beyond merely representing *"vision"*; it also encompasses *"voice"*. This could be understood in the context of the famous proverb, 'children should be seen but not heard'. This well known adage incorporates two elements 'to be seen' and 'to be heard'. It is these two facets, *"vision"* and *"voice"* that constitute the core construct of *"visible-ness"* in this study. *"Visible-ness"* explicates the position the child assumed and the degree to which the child was, or wanted to be, included or excluded in the communication process, in addition to the extent to which the child's communication needs were met. In order to visually present this abstract construct of *"visible-ness"*, a continuum was enacted to demonstrate that two distinct opposing multi-dimensional extremities, labelled *"being overshadowed"* and *"being at the forefront"*, existed within the communication process; either of which children could occupy in their interactions with health processionals (Figure 4).

**Figure 4: Conceptual Extremities of the *"Visible-ness"* Construct**




[184] I use the term construct here, as opposed to concept, because McKenna (1997:8) highlights "if the phenomena are very abstract and the resultant concept is not directly observable or measurable it is often referred to as 'construct'".

### **6.1.1.** Overview of the conceptual extremities of the *"visible-ness"* construct

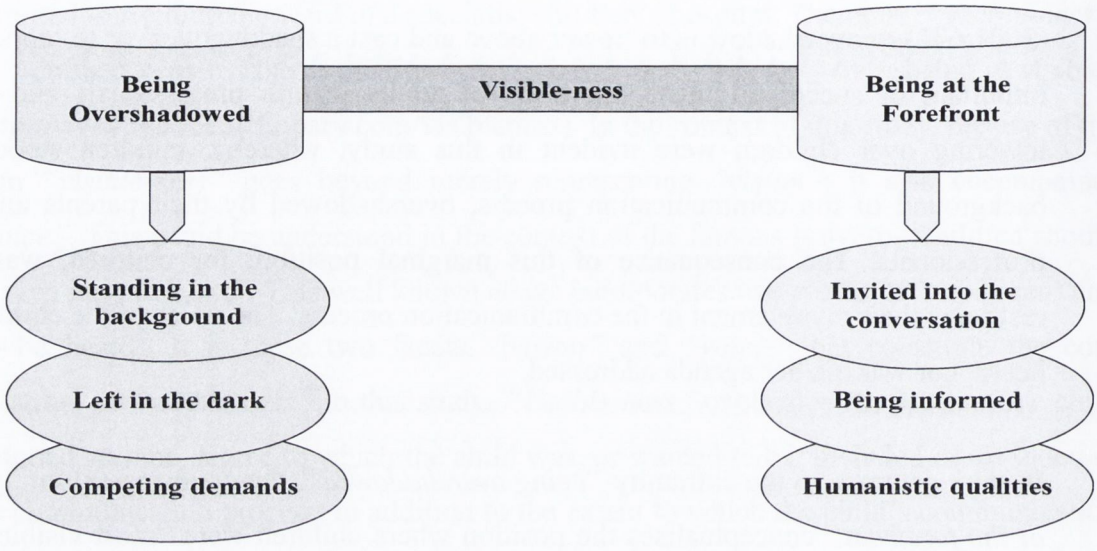
The extremity *"being overshadowed"* conceptualises the "least visible" position children could hold within the communication process. According to Soanes, Spooner and Hawker (2001:632) to overshadow is to 'tower above and cast a shadow over' or to 'appear more important or successful than'. Elements of adults (health professionals and parents) towering over children were evident in this study, whereby, children stood in the background of the communication process, overshadowed by their parents and health professionals. The consequence of this marginal position, for children, was that it restricted their involvement in the communication process. The voice of the child was not heard, nor was his/her agenda addressed.

In stark contrast, to the extremity *"being overshadowed"*, the opposing extremity *"being at the forefront"* conceptualises the position where children were "most visible" within the communication process. Positioned at this extremity, children were seen to dwell at the forefront of the communication process, holding a leading position, with health professionals communicating directly with them, or simultaneous with them and their parents. The implication of "*being at the forefront*" was that children felt valued and respected through their inclusion in the communication process. The consequence of being included was that it facilitated being open to the child's agenda.

### **6.1.2.** Overview of the multi-dimensions of the extremities of the *"visible-ness"* construct

The two opposing extremities, *"being overshadowed"* and *"being at the forefront"*, of the *"visible-ness"* construct were multi-dimensional in nature, each comprising of three dimensions. The three key dimensions of the extremity *"being overshadowed"* were titled *"standing in the background"*, *"left in the dark"* and *"competing demands"*. Directly opposite these dimensions were the three key dimensions of the extremity *"being at the forefront"*, titled *"invited into the conversation"*, *"being informed"* and *"humanistic qualities*", as illustrated in Figure 5.

**Figure 5: Multi-dimensional extremities**
***"being overshadowed"* and *"being at the forefront"***

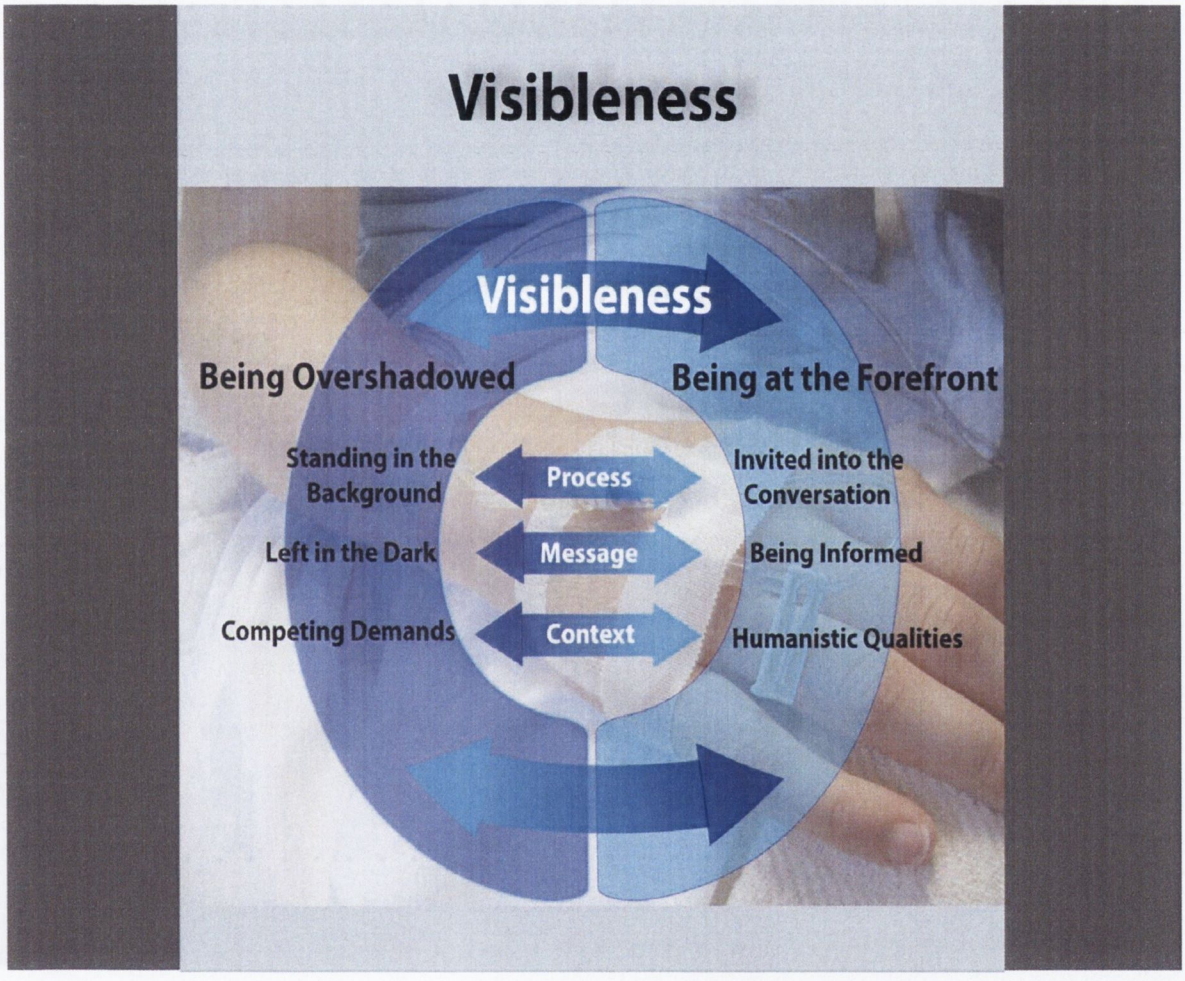



These dimensions of the two extremities of the *"visible-ness"* construct will be presented utilising the trans-circular model of communication (outlined in Section 3.2.1 and displayed in Figure 1) as a framework to illustrate how the dimensions were linked both vertically and horizontally, as shown in Figure 6 below. Within this trans-circular model, communication is conceptualised as a reciprocal *process* in which *messages* are exchanged between two people, a sender and a receiver; all of this process is influenced by the *context* in which it takes place. Keeping in line with this model, the multi-dimensions of the two opposing extremities, *"being overshadowed"* and *"being at the forefront"*, are linked horizontally by using the key headings, *process*, *message* and *context* (see Figure 6), all of which collectively influence the effectiveness of the communication process.

It must be acknowledged that such segregation of the diverse and dynamic concept of communication into these three discrete headings does not recognise the interconnectedness and overlapping of all these elements; *process*, *message* and *context*. Although the multiple dimensions will be presented in a sequential manner, in lived reality, elements expressed within these multi-dimensions often occurred simultaneously.

There is a distinct "haziness" across many aspects of the fundamental features of communication presented within the dimensions. The dimensions are interactive and interdependent and the fluidity of this interconnectedness will be illustrated towards the end of this chapter. Firstly, for ease of presentation and understanding, the *process*, *message* and *context* will be individually described.

**Figure 6: *"Visible-ness"* Construct**



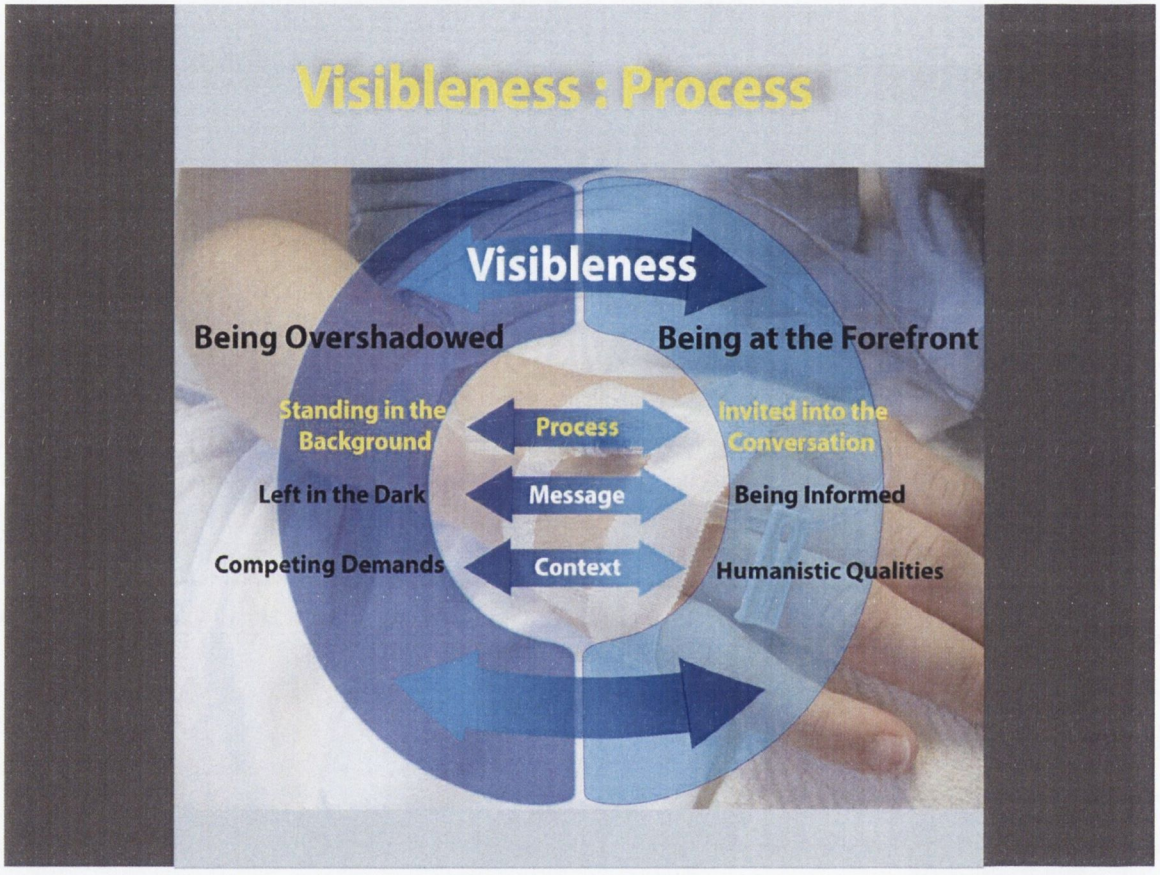

## 6.2. *"Visible-ness"*: Process

### 6.2.1. Introduction

This section describes the interaction *process* as it occurred between health professionals and children, both of whom, at different points, assume the role of sender and receiver

(see Figure 7). This interaction *process* illuminates the degree to which children were directly involved in the communication process and ultimately governed the extremity of the *"visible-ness"* construct that children predominantly occupied; that is whether they occupied the conceptual extremity *"being overshadowed"* or *"being at the forefront"*.

**Figure 7: *"Visible-ness"*: Process**




The degree to which children were involved in communication process and the extremity of the *"visible-ness"* construct children held was determined firstly by the directional flow of the interaction. Health professionals, parents, and children themselves, were influential in affecting the directional flow of the interaction process. For example, if the parent 'butted in' during an interaction taking place between their child and health professional, or if the child 'butted in' during an interaction taking place between their parent and health professional, it resulted in a change in the directional flow of the

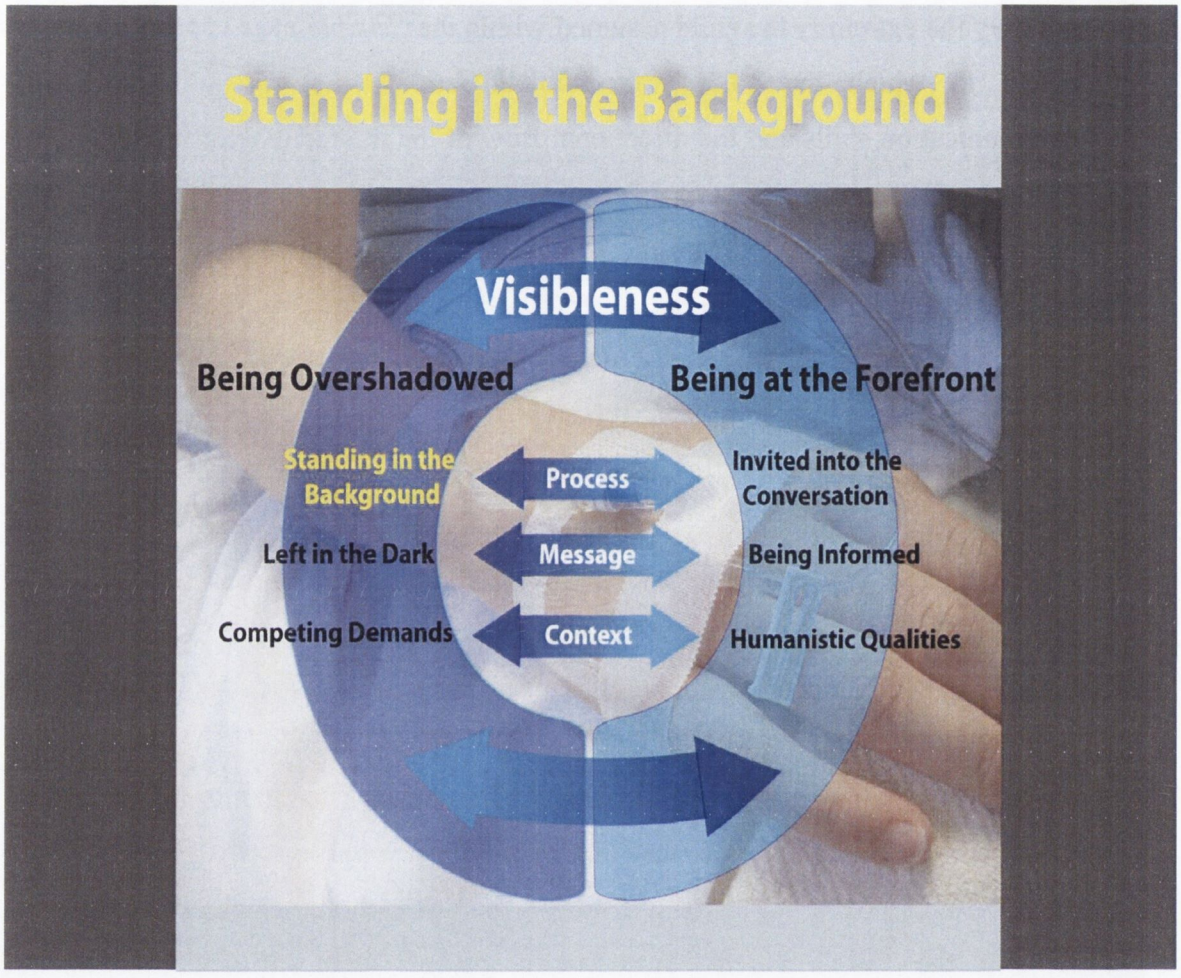
interaction towards the person (either child or parent) who had interjected. Secondly, the child's level of involvement, and extremity of the *"visible-ness"* construct they occupied, was influenced by the communication skills employed by health professionals. Listening, questioning and offering reassurance were key communication skills which determined, not only the extremity the child assumed within the *"visible-ness"* construct, but also, the extent to which the child was involved and his/her agenda addressed. These communication skills and the directional flow of the interaction constitute the *process* of communication, which is comprised of the two opposing dimensions *"standing in the background"* and *"invited into the conversation"*, each of which represents one of the two conceptual extremities of the *"visible-ness"* construct, illustrated above (Figure 7).

### **6.2.2.** "Standing in the background"

*"Standing in the background"* is the first dimension of the conceptual extremity *"being overshadowed"*, which represents one aspect of the *"visible-ness"* construct and constitutes one aspect of the *"process"* of communication, as illustrated below (Figure 8). *"Standing in the background"* encapsulates one of the actual positions children held within the communication process, that of a passive bystander. Children did not merely occupy a bystander position because they were not involved in the communication process, but they were also marginalised by the type of communication skills employed by health professionals. This marginal bystander position was firstly determined by the health professionals' directional flow of the interaction, which was mainly directed towards the child's parent. Furthermore, parents were influential in changing the directional flow of the interaction, if it was directed towards their child, by 'butting in' and disrupting the interaction process between the child and health professional. Secondly, key communication skills employed by health professionals, namely, the predominant use of closed questions, ineffective listening skills and the offer of premature reassurance, further resulted in children occupying a marginal bystander position. Such strategies prevented children from actively participating in the communication process and blocked the expression of children's individual views, concerns and feelings. The consequence of this, for children, was that it not only inhibited their inclusion in the communication process but also enabled both health professionals

and parents to retain power and control the agenda. As a result, children were less empowered and their agenda remained unexplored.

**Figure 8: Dimension *"Standing in the background"***




Children stood in the background of the communication process when the conversation flow was predominantly directed towards their parent(s). In such instances, children were not communicated directly with by health professionals, rather health professionals and parents conversed about them in their presence, while children eavesdropped in the background. For example, during informal conversations, Annette (8 years), Brian (10 years) and Mike (12 years) all informed me that they listened to what the doctor was explaining to their parents about what was wrong with them. These children were passive bystanders, looking-on and listening in, when their parents and health professionals

interacted. While it is appreciated that such eavesdropping may provide a medium for children to acquire information, especially in instances when they are not directly communicated with, it can lead to misconstrued understanding as children attempt to piece together elements of the overheard adult conversation (Deering and Cody, 2002). This was highlighted by Orla (10 years) who told me that although she listened in when the doctors were talking to her parents, she sometimes did not understand what they were saying.

The following observational field note extract serves as an illustration of the context of a typical interaction between a health professional and parent, with the child present. In conversing with each other, the parent and health professional label Rebecca 'she'. This encompassed discussing Rebecca in her presence, rather than addressing Rebecca directly. It resulted in Rebecca being bypassed and portrayed to me an image of Rebecca *"standing in the background"*, overshadowed by her mother and health professional.

> The doctor entered the room and approached Rebecca's bed. The doctor stood at the opposite side of the bed to where mum was sitting and next to him stood a staff nurse. Rebecca's mum stood up. The student nurse allocated to the room for this morning also arrived and she stood beside Rebecca's mum. The curtains were pulled around the bed. Rebecca remained lying on her bed.
> Doctor (to staff nurse): What were the 'obs' [observations] like overnight? Did she have a temperature?
> Staff Nurse: I'll get the chart for you (staff nurse left the room)
> Doctor to Rebecca: Are you sore?
> Rebecca: (nodded head indicating yes)
> Mum: She's sore when she walks… but she's afraid to say anything
> Doctor to Rebecca: Have you gone to the toilet?
> Rebecca: (no response, looked puzzled)
> Doctor to mum: Did she open her bowels yesterday?
> Mum: Yes
> The staff nurse returned with the chart and the doctor turned to look at the chart. He talked to the staff nurse as he went through the chart. He then turned back to the child and mum.
> Doctor to mum: Has she eaten anything?
> Mum: Not since yesterday when she vomited what she ate. She is now fasting since midnight.
> Doctor to Rebecca: Do you feel like eating?
> Rebecca: (nodded head indicating no)
> Doctor to Rebecca: I'm just going to feel your tummy.
> The doctor pulled up Rebecca's Pyjama top just enough to expose her tummy and began pressing and feeling, moving from one area to another.
> Doctor to Rebecca: Is it sore here? (pressing down on child's tummy)
> Rebecca: (nodded head no)

Doctor: ....and here.....
Rebecca: (nodded head yes)
The doctor pressed up and down again.
Doctor: Is it sorer up here or down here?
Rebecca: Up here
Then the doctor pressed her tummy in and out really quickly
Doctor: Which is sorer when press in or out?
Rebecca: In (grimacing / eyes filled with tears)
Mum rubbed Rebecca's arm. The student nurse walked to the sink situated in the middle of the room where she collected some hand towel and on return handed it to Rebecca.
Doctor to mum: We'll probably take her to theatre. I'll have to discuss it with (consultant). It'll be at the end of the theatre list so won't be until this evening.
Doctor to staff nurse: So stay fasting and keep her on fluids
Staff nurse to doctor: Can you chart the fluids?
Doctor charted the fluids.
Doctor to mum: Okay I'll be back later
(Field Notes: Observation: Rebecca 11 years: November 2004)

This conversation between the doctor and Rebecca's mother took place across Rebecca with her mother standing on one side of the bed and the doctor on the other. This clearly paints a picture of adults (health professional and parent) towering above and casting a shadow over Rebecca. Although the doctor did allocate some turns in the interaction to Rebecca, this was principally achieved by asking her closed questions related to physical activities of living and examination. Primarily, the doctor interacted with Rebecca's mother, speaking about Rebecca in her presence. Rebecca listened while in the background. In the next excerpt, from my conversational field notes, Rebecca clearly articulates the consequence, for her, of occupying the background position of the communication process.

Veronica: Tell me about when the doctors come to see you?
Rebecca: They came to see if I was okay, to check how my pain was, then he said he had to check with the higher doctor before bringing me for an operation.
Veronica: What about the operation who told you about that?
Rebecca: The doctor
Veronica: What did he say?
Rebecca: That I was going to have an operation and they were going to take my appendix out and ....mmm well said they were going to put me asleep...they told my mam.
Veronica: They told your mam, how did you feel about that?
Rebecca: Well I think they should have told me as well.

Rebecca: My Dad wasn't allowed to come in with me.
Veronica: Your dad wasn't allowed go into theatre with you

Rebecca: No
Veronica: How come?
Rebecca: 'cause it [operation] was an emergency
Veronica: How did you feel about that?
Rebecca: I didn't mind

At this stage a porter arrived with a theatre trolley to take another child in the room to the operating theatre.
Rebecca: That's the same man that brought me to theatre…and nurse
We sat for a moment in silence, watching the other child get onto the trolley.
Veronica to Rebecca: How did you feel when you were getting on the trolley to go to theatre?
Rebecca: I was shaking (shaking hands)
Veronica: How come?
Rebecca: I was worried they'd hurt me…….and near tears when my dad left, he left me at lift….you know he could go as far as the lift down the big long corridor and near the x-ray that lift.
(Field Notes: Informal Conversation: Rebecca 11 years: November 2004)

As a result of the interaction taking place between the doctor and Rebecca's mother, Rebecca's feelings and concerns were not explored. In relation to her operation, Rebecca highlighted pain as her chief worry and described non-verbal indicators of her fear, when she stated she was 'shaking' climbing onto the trolley to go to the operating theatre. Although Rebecca initially stated that she 'didn't mind' when her father was not allowed to accompany her into the operating theatre, later she portrayed her extreme sadness, by affirming that she was near tears, when her father had to leave because he was not allowed to accompany her into theatre. This marginal position created a sense of isolation and loneliness for Rebecca.

As seen in the above scenario between Rebecca, her mother and the doctor, parental presence was influential in determining the health professional's directional flow of the interaction. Parents themselves often influenced the course of the interaction, which subsequently determined the level of the child's participation. For example, at times parents were observed 'butting in' to the communication process, when the interaction took place between the health professional and child. When parents interjected not only did this block the child's response, it resulted in a shift in the topic and flow of the interaction, as illustrated in the observational extract below.

Two nurses came to the room door with the medication trolley. One of the staff nurses approached Tom who was sitting on a stool beside his bed. Tom's mother

was sitting on Tom's bed. The staff nurse leaned over to come down to Tom's level.
Staff nurse to Tom: How are you?
Tom: Fine
Staff nurse: Are you sore? Do you want something for pain?
Tom's mother: I was just confused about when he was going home, was his temperature up last night?
Staff Nurse: A little bit ....it's just if he got sick he'd have to come back in so it is better to stay in to make sure.
(Field Notes: Observation: Tom 13 years: November 2004) [185]

It is unknown whether parents consciously or subconsciously 'butt in'. Parents themselves may feel excluded and their agenda neglected, or possibly there is a natural tendency for parents to 'butt in', for it was not unique to interactions taking place on the children's ward. This is highlighted in the following field note extract in which Orla described to me a situation which took place when she went to visit her general practitioner (GP).

> Orla told me that she went to see her doctor [GP] three times a month....may be more she said for she wasn't sure....she couldn't remember his name....She told me she remembered him asking her a question about her epilepsy. She said her mum whispered the answer to her. She stated that she mouthed back to her mum, no that's not the right answer....but then her mother answered for her. Orla relayed that the doctor had then said to her mother, excuse me I didn't ask you [mother]
> (Field Notes: Informal Conversation: Orla 10 years: January 2005)

These findings concur with previous studies, investigating medical interactions and decision-making, which found consultations to be mostly dyadic exchanges between parents and health professionals, with children largely marginalised (Strong, 1979; Silverman, 1987; VanDulmen, 1998; Tates et al, 2002; Young et al, 2003; Savage, 2003; Coyne et al, 2006). In this marginalised position, children stand in the background of the communication process, overshadowed by health professionals and their parent(s). The implication of this, as highlighted in this study, is that not only are children excluded, but children's views, concerns and worries remain largely unexplored. Parental presence was not exclusively responsible for resulting in the child occupying a marginalised position in the communication process. The type of communication skills utilised by health

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[185] In this encounter, Tom's mother interrupted the staff nurse who was conversing with Tom. Tom's mother changed the topic of the conversation to gain information about another matter of concern to her. This diverted the nurse's attention away from Tom to his mother, thus blocking the exchange between Tom and the nurse.

professionals also resulted in children's marginalisation and deterred them from expressing their views and concerns. One such skill was the questioning style employed by health professionals.

There are several different forms of questions, each of which shift the interaction in diverse directions and yield distinctive responses (Stevenson, Grieves and Stein-Parbury, 2004). Children were seen to stand in the background of the communication process when health professionals' predominantly employed closed questions. This is because closed questions are a directive type of exploration and are health professional driven and focused (Stevenson, Grieves and Stein-Parbury, 2004). Closed questions do not necessarily address the child's agenda. Instead, closed questions have a specific fact finding purpose and can be quickly and easily answered with short monosyllabic responses such as yes, no, not sure or with a short phrase (Petrie, 1997; Faulkner 1998; Roter, 2002). Therefore, while closed questions may allow some reply, they restrict the respondent's answer and involvement in the interaction process. This is illustrated in the scene below, taken from my observational field notes, where, although the anaesthetist interacts with Ann in her parents' absence; the predominant use of a series of closed questions places Ann on the periphery of the communication process.

> The anaesthetist pulled up a chair and sat down at one side of the foot of the bed putting Ann's medical chart on the bed in front of him and opened it. He started to go through the chart. Ann was at the other side of the bed standing up. The TV was on over our head.
> Anaesthetist: I'm the anaesthetist….. I'm going to put you asleep for the operation
> Ann: Today
> Anaesthetist: No tomorrow I'm going to do nothing today…… So how are you?
> Ann: Fine (smiled / looked over at me / put hand to face covering her mouth)
> Anaesthetist: Can I ask you, have you any problems?
> Ann: Problems
> Anaesthetist: Have you any problems other than your eyes?
> Ann: No
> The anaesthetist wrote in the medical chart on the bed. Ann turned her head away from the anaesthetist and looked up at the TV.
> Anaesthetist: Can I ask, are you taking any medicines?
> Ann: …..em sorry (leaning across the bed)
> Anaesthetist: Are you taking any tablets?
> Ann: No
> Anaesthetist: Have you any loose teeth?
> Ann: No (putting her hand to her mouth)
> Anaesthetist: How's your chest ….breathing …any asthma?

Ann: No
Anaesthetist: Have you had any operations before?
Ann: No
Anaesthetist: Nothing
Ann: No (nodding head)
Anaesthetist: What class are you in?
Ann: Second
Anaesthetist: Good
Anaesthetist: Can I listen to your chest?
The anaesthetist got up and walked along the foot of the bed to Ann. He stood above Ann and listened to her chest. When finished, he sat back down.
Anaesthetist: Can you open your mouth?
Ann leaned across the bed so the doctor could see inside her mouth.
Ann: One of my teeth is black 'cause I have a filling
Anaesthetist: That's fine….okay that's fine
The anaesthetist got up and left.
(Field Notes: Observation: Ann 8 years: January 2005)

In the above excerpt, the interaction was initiated and controlled by the anaesthetist and followed a direct question answer format. This type of exploration dis-empowers the patient with the health professional remaining in control (Stevenson, Grieves and Stein-Parbury, 2004). The communication process is reduced to a mere checklist of closed questions whereby topics are introduced which focus on what the anaesthetist wants to know according to his agenda. A level of tokenistic involvement was evident when Ann was asked, what class are you in? However, Ann was not given an opportunity to openly express her views, concerns or feelings. Following the above observation I spoke with Ann, who informed me that she was nervous and scared about her operation, as illustrated in the excerpt below.

Ann to Veronica: I never had any problems or been sick with asthma or anything like that …like flu… I'm always well
Veronica: Who was that that came to see you?
Ann: The doctor who is going to do the operation…when he said that I thought today he was doing the operation today…. I was nervous and scared …like about the operation
Veronica: You were scared and nervous what about?
Ann: What they were going to do ….like …cut my eye open.
(Field Notes: Informal Conversation: Ann 8 years: January 2005)

A similar interaction was observed when the doctor came to visit John after his operation as illustrated in the extract below, taken from my observational field notes. John's parents were not present at this time.

A surgical register (doctor) dressed in green theatre scrubs entered the room. He stood at the end of John's bed, below where John was sitting.
Doctor: John, how are you feeling?
John: Fine
Doctor to Veronica: Stop the fluids
The doctor proceeded to disconnect the drip from the IV site.
Doctor to John: Any bowel motion?
John: What?
Doctor: Any bowel motion.... number 2
John: Ah ya... just now
Doctor: What was it like?
John: OK.....well still a bit runny.....different like
Doctor: can I exam your back passage?
John: What?
Doctor: Can I exam you ...down there (pointing down)?
John: Oh OK
John got up on to the bed, the doctor went to the sink to wash his hands and put on gloves. He returned and pulled the curtains around the bed.
Doctor to John: OK ...just bend your knee (placing hand on child's knee)
John bent his knee up.
Doctor: OK....sorry John
John (grimace)
Doctor: Is that sore?
John: Ya ...a bit....(grimace)
Doctor: Sore here
John: Ya sort of
Doctor: OK John
The doctor went to sink to remove his gloves and wash hands. I pulled back the curtains. The doctor returned.
Doctor to John: Will you drink some fluids...and sit up.
John got up off the bed to sit in the chair. The doctor left.
(Field Notes: Observation: John 13 years: February 2005) [186]

Like Ann above, John's views, feelings or concerns were not explored. Despite the fact that questions were directed towards John, which could be viewed as allocating John a

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[186] I acknowledge the sensitivity of this interaction/examination. In order to set this observation within context I recorded this reflective note following my presence in this situation: "When the doctor arrived into John I was present. I recognised the doctor and he subsequently knew me as a nurse and clearly regarded me as so asking me to 'stop the fluids', despite the fact that I was dressed in ordinary clothes. I attempted to intervene and explain my current change in role, as researcher. Yet, the doctor proceeded to interact with John and commenced the examination. I turned in search of a nurse but no one was within my field of vision. Realising the sensitive and invasive nature of the examination I was reluctant to leave John alone, despite the uncomfort I felt. Instinctly, it felt the correct thing to do at the time; that is to remain with John. Afterwards, I ask - was it appropriate for me as researcher to stay? However, I believe it would have been unethical to leave" (Reflective Fieldnotes: February 2005). This illustrates the fine divide that can arise between the role as researcher and the role of nurse when undertaking ethnographic research within a clinical setting.

turn to speak, the questions posed were predominantly bio-medically focused; dictated by the doctor according to his agenda. While asking patients closed questions is legitimate to establish what is wrong with them and to instigate appropriate interventions (Faulkner, 1998; Gwyn, 2002; Stevenson, Grieves and Stein-Parbury, 2004); closed questions do not explore the patient's agenda. To ensure all aspects of patient's well-being are addressed, health professionals must also be prepared to explore thoughts, perceptions, feelings and reactions experienced by patients in an attempt to understand the patient's point of view (Faulkner, 1998; Stevenson, Grieves and Stein-Parbury, 2004; McCabe and Timmins, 2006). Possibly, one reason for the predominant use of closed questions is that it affords health professionals with a sense of interpersonal safety/security (Faulkner, 1998; Stevenson, Grieves and Stein-Parbury, 2004; Hays et al, 2004). This enables health professionals to distance themselves from the patient and avoids the unpredictable nature of responses to open-ended questions; maintaining the communication process at a less personal and superficial level (Faulkner, 1998; Stevenson, Grieves and Stein-Parbury, 2004; Hays et al, 2004).

The provision of premature reassurance was another tactic/strategy that marginalised children and avoided addressing their topics of concern. This concept of premature, or false, reassurance has been extensively reported elsewhere (Maguire and Pithceathly, 2002; Stevenson, Grieves and Stein-Parbury, 2004). It is referred to as meaningless reassurance (Tamparo and Lindh, 2000), because as its consequence, rather than acknowledging children's concerns or worries, it acts as a silencing mechanism inhibiting children's ventilation of their concerns and feelings. Not only does offering premature reassurance block children's expression of their concerns, it dismisses, belittles and minimises any worries/feelings they may have, placing them on the periphery of the health professional agenda. For example, Sue (12 years) informed me that her pain was implicitly dismissed by the doctor when he said to her, "you're grand the pain can't be that bad". In this instance Sue felt misunderstood and dissatisfied when the doctor chose to ignore her level of pain. This implies to children that their concerns are insignificant. By not being encouraged to express their concerns, children harbour their fears and feelings internally. This results in non-therapeutic communication (Faulkner, 1998).

In the following observation, recorded shortly after Gary's admission to the children's ward, a student nurse responded to Gary's statement, I might have to get my appendix out with oh you look like a strong boy.[187] This neglected to explore with Gary his concerns, worries or feeling about having his appendix removed and his impending operation, as illustrated in the extract below.

> A student nurse entered the room and stood at the end of Gary's bed.
> Student nurse: how are you darling? (looking around the room)
> Gary (no response)
> Student nurse: how are you darling? (looking at Gary and leaning slightly forward towards him)....I saw you holding your stomach there... are you okay?
> Gary: I might have to get my appendix out
> Student nurse: oh you look like a strong boy.
> (Field Notes: Observation: Gary 11 years: November 2004)

Later, when conversing with Gary, about how he felt about his impending operation, he relayed to me that he did not really know how he felt because he never had an operation before. He stated he did not really mind and he hoped to get a big scar, just like his cousin who had previously had his appendix removed. Gary relayed that he knew he would not be awake for the operation anyway, when they would "cut" him. He went on to say that he would be a bit scared in the hospital that night though, not because of his impending operation, but because his parents were not able to stay with him.

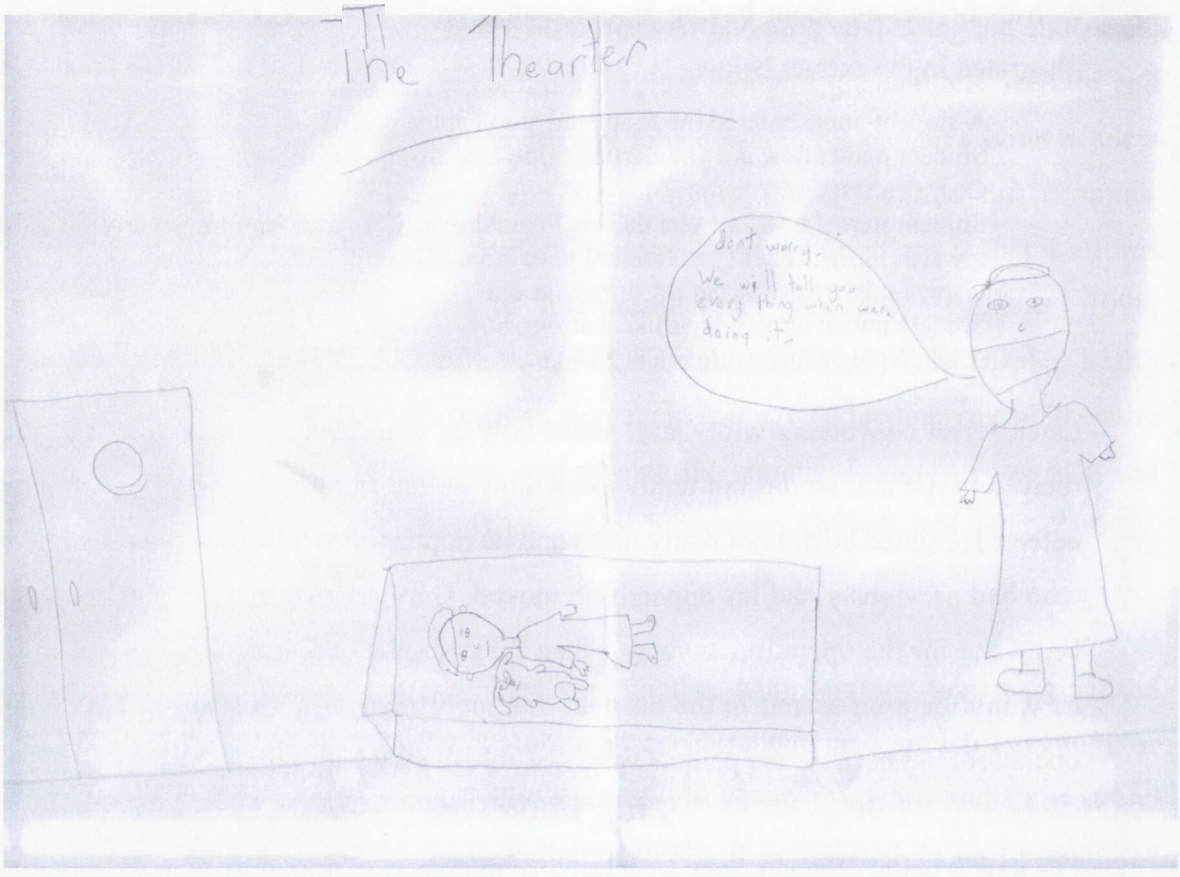
Displayed below, Sinead drew a picture of "the thearter" [theatre]. Sinead is lying on the bed with her teddy dog "floppy". The doctor is standing beside Sinead's bed. Sinead relayed that he was wearing green clothes, a mask, "so germs won't get in" and a hat, "so hair won't fall in". Sinead wrote in a speak bubble what the doctor had said to her "don't worry we will tell you every thing when we're doing it". Although this may have orientated Sinead to what was happening and assisted in allaying certain anxieties about what was happening, it did not explore concerns or worries specific to Sinead, but rather focused on the world of the health professional and what they were doing. Speaking with Sinead about how she felt at this time in theatre, she stated "scared" because her mother

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[187] This is interesting as Gibson et al (2005) reported that children would not tell anyone they were worried because they wanted to be brave and strong. Are these the connotations that health professionals are portraying to children?

did not go with her; although her teddy dog "floppy" was allowed. Sinead had never been in hospital before, but stated she had seen an operation room on a television programme.

**Drawing 4: Sinead 9 years (January 2005)**




This, culturally conditioned response of offering premature reassurance is further illustrated in the following scene of an interaction observed between John and a clinical nurse manager, who was assisting a staff nurse to administer intravenous antibiotics to John.

> The nurses arrive to administer John's intravenous antibiotics. A Clinical Nurse Manager (CNM) & Staff Nurse enter the room and approach John's bed.
> CNM to John: Now John just give you your antibiotics (taking the brake off the bed, pulling the bed out a bit from the wall)
> The staff nurse walked up the inside of the bed next to the wall where the IV pump was and the CNM went and stood at the opposite side of the bed. John was sitting up in bed.
> CNM to John: Now just check you off first.
> The staff nurse checked John's name-band on his wrist with the CNM. Both the staff nurse and CNM leaned across the bed to check the number from John's wrist

name-band against his drug cardex. The CNM then talked the staff nurse through the procedure of giving the IV antibiotics.
CNM to John: Sorry John for talking across you …I'm just teaching (name of staff nurse) how to do these
After a few minutes when the staff nurse was giving the IVs the CNM spoke to John CNM to John: Your friends coming in today?
John: Don't know
John to CNM: Do you know when this is coming out (pointing to drain)?
CNM to John: I don't know …...they will shorten it tomorrow …its won't be sore just the sensation of it when they pull it ….they will shorten it a bit everyday so in a few days it'll come out …see how it does.
John looked sad and didn't say anything.
CNM to John: You browned off
John to CNM: Ya …(nodding head teary eyed)
CNM: It feels like longer than 2 weeks since you're in.
John: Ya
CNM: You will get better it won't be too long now.
The staff nurse doing the IVs was now having some pump problems so the CNM turned her attention back to the staff nurse and once they were finished said to John
CNM: Okay John.. see you later
(Field Notes: Observation: John 13 years: February 2005)

In the above excerpt, although the clinical nurse manager identified the cue ventured by John, that he was "browned off" she failed to explore the reason why teary eyed John felt this way. She made her own assumptions, that John's fed up feeling was related to his length of stay in hospital and proceeded to offer premature reassurance saying, you will get better it won't be long now, then refocused herself on the task of supporting the staff nurse in her administration of the intravenous antibiotics. This equates with Faulkner's (1998) second level interaction, this is, that although the patient may give a hint of how he/she is feeling any further exploration of such feelings are blocked by the health professional offering premature reassurance. This was also described by Morse et al (1992) as A-engaged-detached response. Interestingly, John had interjected earlier in the conversation to raise an issue of concern for him, which was his drain. Indeed, while conversing with John before this interaction took place, John had informed me about his drain. He told me that the drain was inserted one night previous when he had developed an extremely bad pain in his stomach. John stated that the purpose was to drain all the "stuff" from where his appendix burst. Although John told me his pain was better since the drain was inserted he found the drain bag very "annoying".

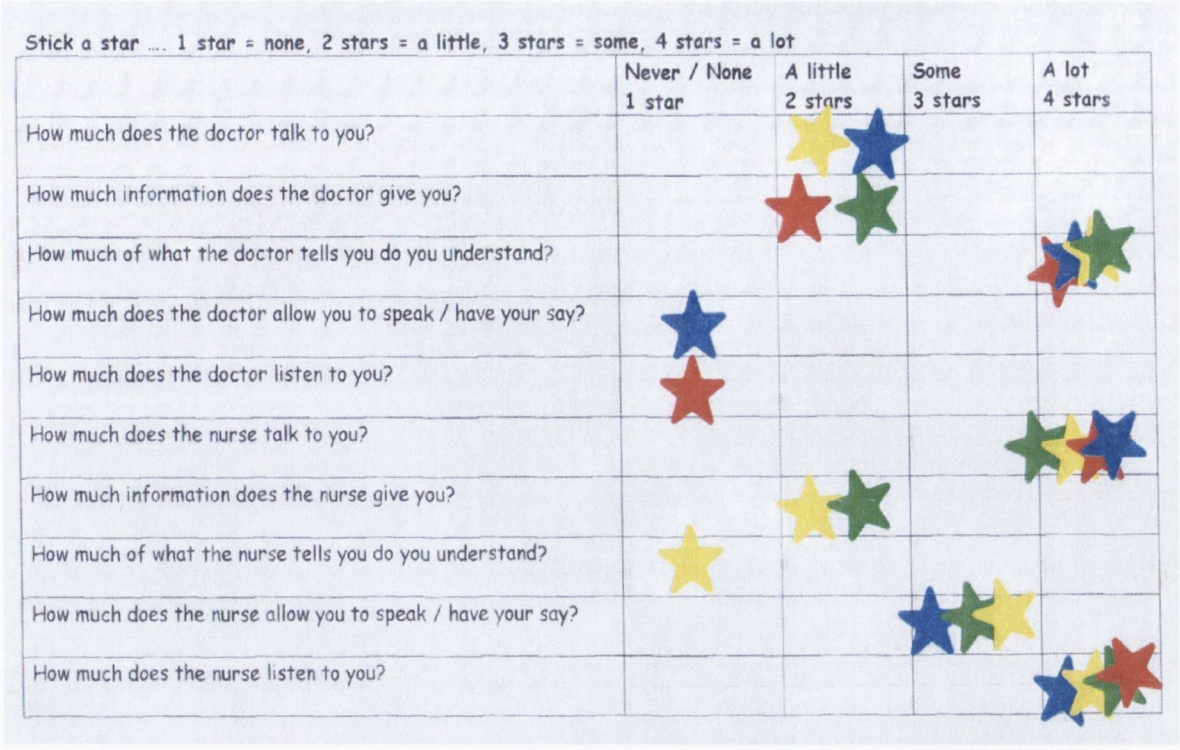
Several authors have suggested an increased incidence of blocking behaviours, with a reluctance to explore patients concerns, when patients disclose emotional cues because of the fear of being unable to handle not only the patients but also staffs' own emotional consequences (Morse et al, 1992; Booth, Maguire and Butterworth, 1996; Tamporo and Lindh, 2000; Maguire and Pitceathly, 2002). However, this minimises the uniqueness of feelings, reflecting to the child that his/her concerns are of limited importance or interest to the health professional (Tamporo and Lindh, 2000; Stevenson, Grieves and Stein-Parbury, 2004). There is the extreme risk that if children become to believe that expressing and sharing their views and concerns are not permissible they will carry this conception forward into their adult life (Petrie, 1997; Faulkner, 1998). By encouraging children to express their views and feelings, it is possible to demonstrate to them that their views and feelings are legitimate (Faulkner, 1998).

In this study not offering children an opportunity to voice their concerns and worries meant children often felt not listened to. This further marginalised children placing them in the background of the communication process. For example, in response to the question, how much does the doctor listen to you, on the stick-a-star quiz, displayed below (stick-a-star quiz 2),[188] Sinead allocated the doctor one star stating that the doctor never listened to her. When asked for an example of an instance when the doctor did not listen to her, Sinead informed me that she felt not listened to when, although the doctor had told her she needed to have her appendix taken out, he then just walked away.

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[188] In the stick-a-star quiz, described previously (section 4.12.3.2), children were presented with a series of open-ended questions about communicating with health professionals. To answer these questions, children allocated stars, 1 star (none / never), 2 stars (a little), 3 stars (some) or four stars (a lot), to health professionals. The researcher then further explored with children, why they chose the number of stars they did for the health professional.

**Stick-a-Star Quiz 2: By Sinead 9 years: January 2005**



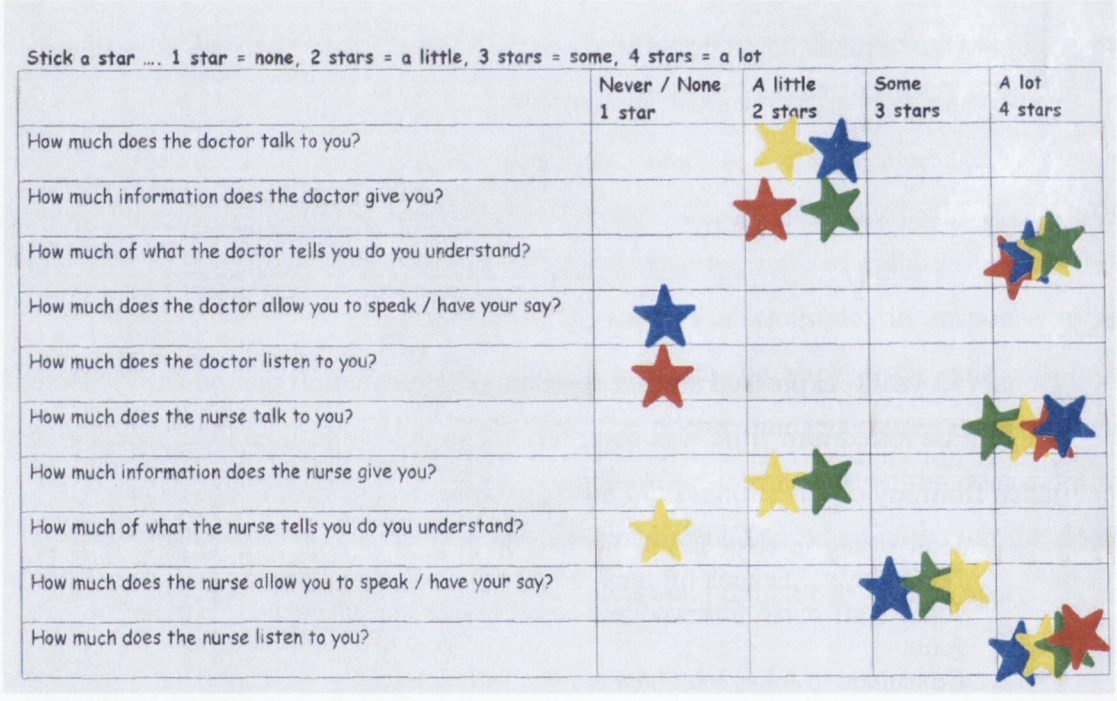

Donal (12 years) expressed similar sentiments to me stating that when the doctor came to see him he asked him if he was sore, felt his stomach and then just left. This next scene, taken from my observational field notes, exemplifies the art of "not listening".

> John sitting in chair beside his bed, he had headphones on and was listening to DVD player…he took off the headphones. Consultant (dressed in suit) stood beside John. Staff nurse followed and stood beside consultant both standing in front of John.
> Consultant to John: John how are you feeling today?
> John: Tired …I didn't sleep very well
> Consultant to staff nurse: Is there much coming out of that (pointing to drain at John's left side)
> Staff nurse: 45mls in 24hours
> Consultant: Is it sore (touching John's tummy)?
> John: Ya (placing hand near the consultants)
> Consultant to staff nurse: We'll leave it until tomorrow and see then
> Consultant to John: Are you eating?
> John: …em not really
> Consultant: Why not? You have to eat
> John: Just not really hungry
> Consultant to staff nurse: Lucozade…give him one to drink
> Staff nurse: He had some cornflakes this morning
> Consultant: Lucozade…every beside should have one, do you have any?

Staff nurse: Yes…should have some in fridge
Both consultant and staff nurse walked away. John put back on his headphones.
(Field Notes: Observation: John 13 years: February 2005) [189]

In support of these findings, when completing the stick-a-star quiz, Sinead clearly articulated that she was not allocated a turn to speak by the doctor. As illustrated below (stick-a-star quiz 3), in response to the question, how much does the doctor allow you to speak/have your say? Sinead stated "never" and allocated the doctor "one star" accordingly.

**Stick-a-Star Quiz 3: By Sinead 9 years: January 2005**




Not being allocated a turn to speak, not only prevented Sinead from having a say, but as a consequence, her feelings and concerns were not explored. Sinead informed me that the

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[189] In response to the question "how are you feeling", asked by the consultant, John stated that he was tired because he did not sleep very well. However, the consultant failed to acknowledge John's response. Rather, he changed the topic of the conversation to focus on his own agenda, turning to the staff nurse to inquire about the output from John's drain. By changing the topic and direction of the conversation the consultant avoided addressing the topic raised by John. It is unknown whether the consultant consciously or sub-consciously ignored John's cue to discuss his agenda. Although the consultant redirected the conversation back to John, it involved asking a sequence of closed questions, about physical activities of living, thus further demonstrating the consultant's attention to his own agenda, neglecting to explore John's worries and concerns/agenda.

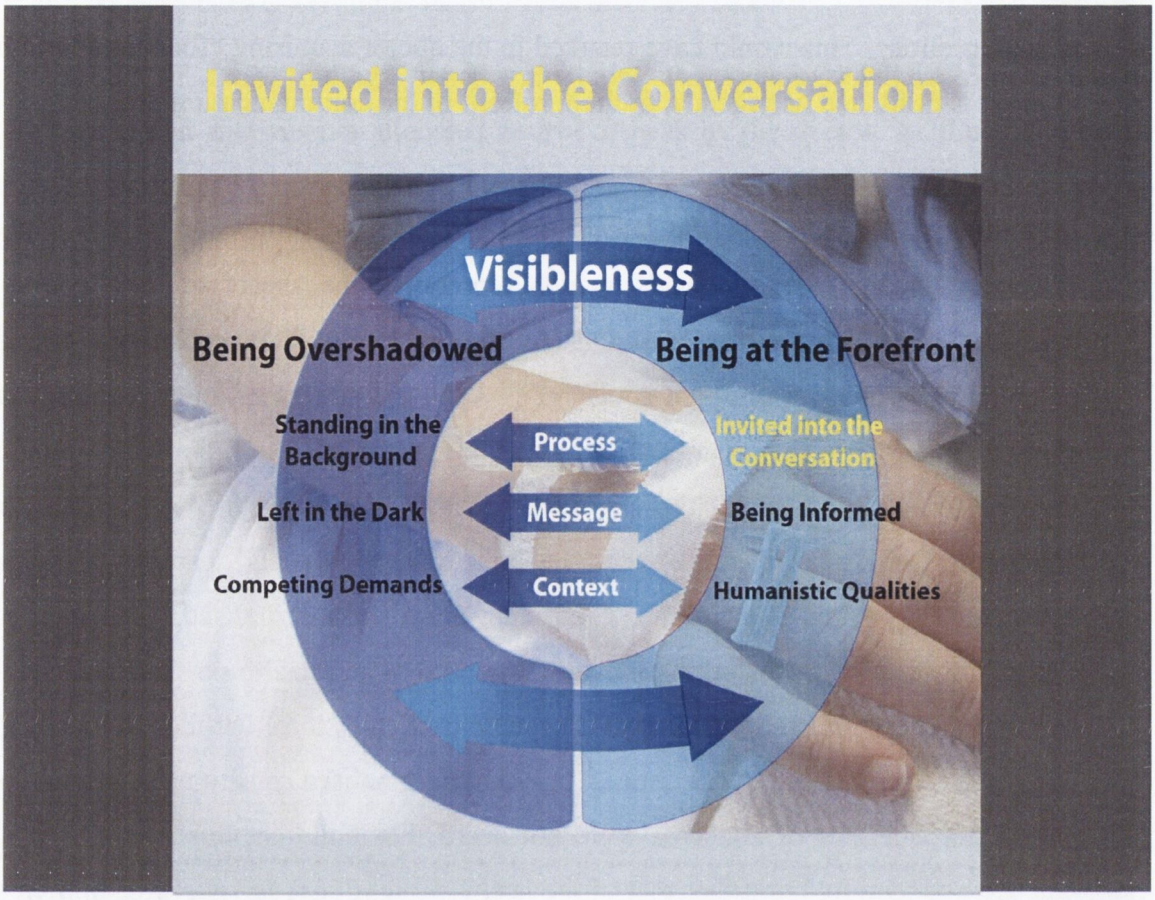
doctor could have given her more say by exploring with her, how she was feeling and if she was scared or worried about her impending operation or by giving her an opportunity to ask questions. This would have resulted in the doctor acquiring "four stars" and helped to move Sinead, and her agenda, to the forefront of the communication process.

In summary, *"standing in the background"* is the first dimension of the conceptual extremity *"being overshadowed"*, which represents one aspect of the *"visible-ness"* construct. This dimension, *"standing in the background"* encapsulates one of the potential positions that children could hold within the communication process; that of a passive bystander. This marginalised position portrayed itself through a number of instances, mainly when children were not allocated a turn to speak. Instead communication took place between health professionals and parents with children eavesdropping in the background. Children were also marginalised when their parents 'butted in' to interactions taking place between them and health professionals and when health professionals predominately employed closed questions, ineffective listening skills and offered premature reassurance. In this marginalised position, children's views, experience, feelings or concerns were not heard. For children, this meant their agenda was not attended to, but rather that of the health professional and parent. Children's level of involvement in the communication process was restricted. This maintained a one way process of superficial communication that was not patient focused.

### **6.2.3.** "Invited into the conversation"

In direct opposition to the dimension, *"standing in the background"* is the first dimension of the opposing conceptual extremity *"being at the forefront"*, which has been titled, *"invited into the conversation"*, illustrated below (Figure 9 below). *"Invited into the conversation"* refers to a second stance children could hold within the communication process; this was a frontal position.

**Figure 9: Dimension *"Invited into the conversation"***




In this position, attention was focused on the child, inviting him/her into the communication process by allowing him/her an opportunity to have his/her say. This frontal position that the child could assume was determined by, firstly the directional flow of the interaction, in which health professionals allocated the child a turn to speak in the conversation. Children also held an influential role in determining the directional flow of the conversation, thus influencing their own level of involvement in the communication process. They did this by initiating interactions with health professionals and/or by 'butting in' to conversations which took place between health professionals and their parents. Secondly, health professionals' employment of key communication skills, such as open-ended questions, effective listening and giving the child an opportunity to ask questions, resulted in the child occupying a frontal position. The consequence of employing these strategies, for children, was that it encouraged them to express their

subjective experience, enhanced their active participation, gave them some sense of control and attempted to address their agenda.

Children occupied the forefront of the communication process when health professionals communicated directly with them. Helen (12 years) felt health professionals were more inclined to communicate directly with her when her parents were not present. This suggests that parental presence was an influential factor in determining whether health professionals communicated directly with children or not. However, there were other instances, highlighted by children and observed by me, where health professionals would speak with children alongside their parents. This demonstrates that parental presence did not necessarily, exclusively, result in the marginalisation of children in the communication process. The following extract, from my observational field notes, serves as an illustration of both Chloe and her family being involved in the communication process.

> When they [Chloe, physio & parents] got back to Chloe's bed after practicing using the crutches the physiotherapist stood at the top of the bed beside Chloe, who had sat back onto her bed and her mum and dad stood at the bottom end of the bed. The physiotherapist spoke to Chloe....for the first while until you get used to the crutches have someone with you and if you can't manage the stairs go up and down on your bum using your good leg. Then the physiotherapist turned to Chloe's mum and dad to tell them.....initially stay with her and watch her going up and down the stairs. Next the physiotherapist spoke again to Chloe saying....when the cast comes off you will need physiotherapy then...but not now I'm happy that you are ready to go home when the doctors are happy. The physiotherapist told Chloe's mam and dad...so you can contact me then....when the cast comes off as she'll need physiotherapy then... and I'll see about getting somewhere closer to home to organise physiotherapy so you won't have to come back here twice a week...so I'm happy for her to go home. Finally the physiotherapist closed the interaction by asking Chloe, do you feel ok using the crutches? Chloe responded...Ya grand. (Field Notes: Observation: Chloe 16 years: November 2004)

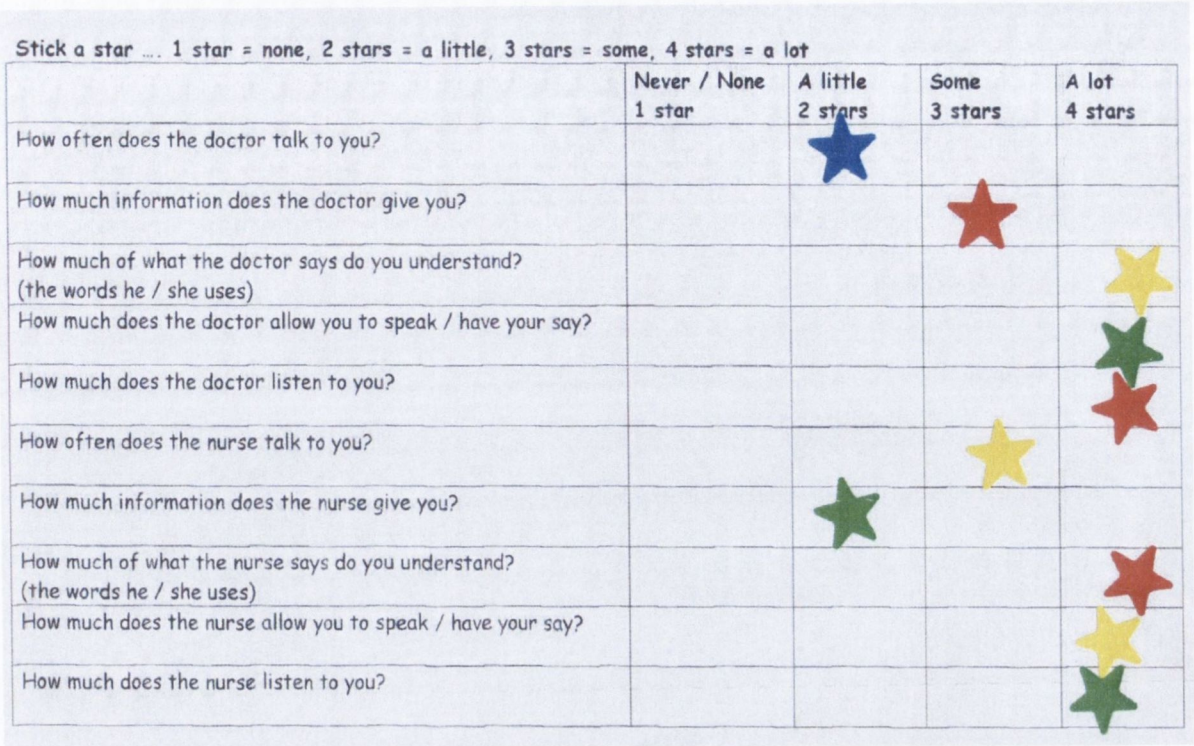
Chloe reiterated this point when we spoke informally, informing me that although the doctors talked to her mother and father more than to her they also talked to her. This portrays partnership qualities and elements of family-centred care. The next scenario, taken from my observational field notes, is a further illustration of a situation when a health professional, despite the presence of the child's parent, also invited the child into the conversation.

Rebecca was lying on her bed. Her dad was sitting in a chair beside her bed. The anaesthetist (dressed in green scrubs and a white hat) arrived. I stood at the end of the bed. The anaesthetist walked towards dad, he was carrying a sheet of paper in his hand.
Anaesthetist to dad: Hi, I'm the anaesthetist (standing beside dad who remained seated). I was asked to see her in case she's going to theatre later. When she (child) had her MRI previously did they put her asleep for it?
Dad to Rebecca: Were you put to sleep when you had your MRI?
Anaesthetist to Rebecca: When you had your MRI did they put you asleep
Rebecca (head nodded yes)
Anaesthetist to dad: When was the drip started? (pointing to IV pump)
Dad: Tuesday
Anaesthetist to Rebecca: Are you thirsty?
Rebecca: (nodded head no)
Anaesthetist to Rebecca: Can you stick out your tongue for me?
Rebecca stuck out her tongue and the anaesthetist leaned down over her to look at her tongue.
Anaesthetist: Okay
Anaesthetist to Rebecca: Do you have any questions?
Rebecca: Am I going to have my appendix out?
Anaesthetist: Yes
Rebecca: What time?
Anaesthetist: I can't say……..it's hard to say with theatre…(pause)….okay.
The anaesthetist left the room.
(Field Notes: Observation: Rebecca 11 years: November 2004) [190]

Like Rebecca above, other children also felt they were given an opportunity to have their say when they themselves got to ask questions. For example, in response to the question, how much does the doctor allow you to speak/have your say, on the stick-a-star quiz illusrated below (stick-a-star quiz 4), Rachel awarded the doctor four stars for giving her a lot of say. When probed further for an example of when the doctor had given her a say, Rachel relayed to me that she was given an opportunity to ask questions. Rachel went on to say that she did not need to ask anything, however valued being given the opportunity to ask questions. Rosie supported Rachel's view stating the nurse gave her some say (three stars, illustrated below on stick-a-star quiz 5) when she allowed her to ask questions. She relayed that she asked about going home and her oxygen mask.

[190] In this scenario, although the anaesthetist initially interacted with Rebecca's father, at a later stage in the conversation, he turned towards Rebecca and invited her to participate in the interaction. Rebecca was afforded with an opportunity to address her agenda, by been asked if she wanted to ask any questions. This helped to bring Rebecca to the forefront of the communication process.

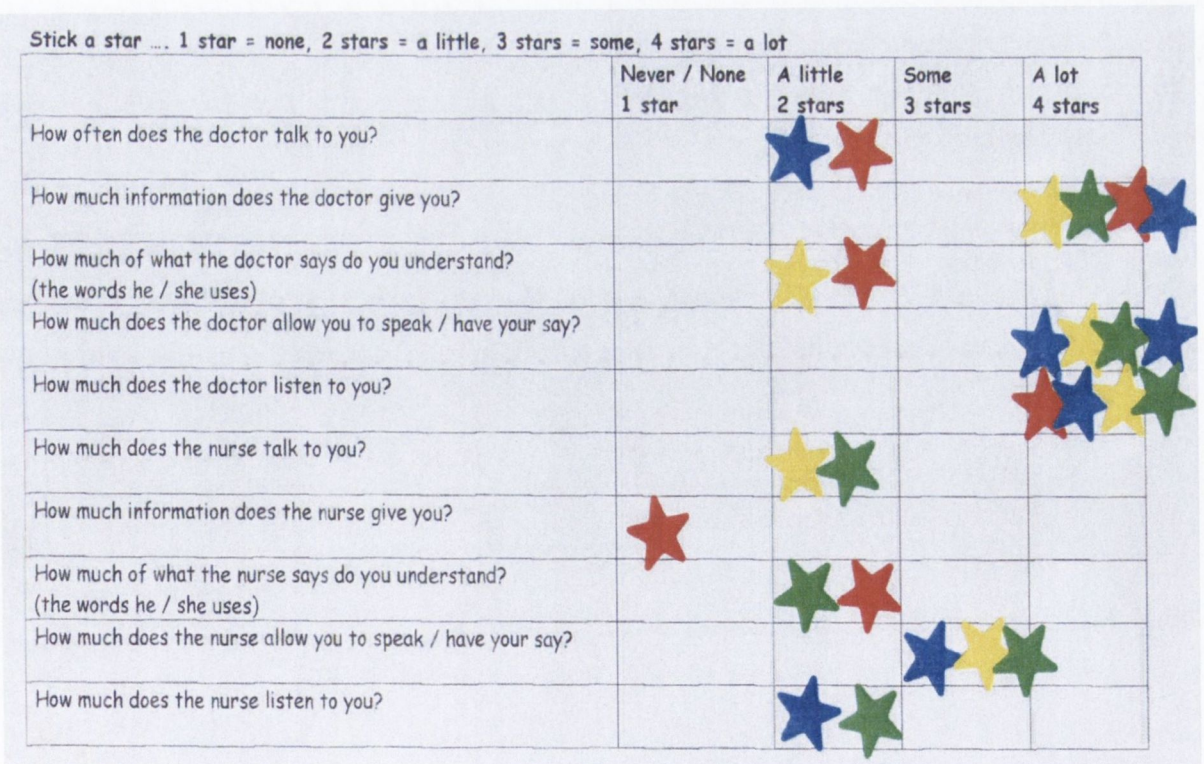
## Stick-a-Star Quiz 4: By Rachel 9 years: February 2005



Stick a star .... 1 star = none, 2 stars = a little, 3 stars = some, 4 stars = a lot

| | Never / None 1 star | A little 2 stars | Some 3 stars | A lot 4 stars |
|---|---|---|---|---|
| How often does the doctor talk to you? | | | | |
| How much information does the doctor give you? | | | | |
| How much of what the doctor says do you understand? (the words he / she uses) | | | | |
| How much does the doctor allow you to speak / have your say? | | | | |
| How much does the doctor listen to you? | | | | |
| How often does the nurse talk to you? | | | | |
| How much information does the nurse give you? | | | | |
| How much of what the nurse says do you understand? (the words he / she uses) | | | | |
| How much does the nurse allow you to speak / have your say? | | | | |
| How much does the nurse listen to you? | | | | |

## Stick-a-Star Quiz 5: By Rosie 11 years: February 2005



Stick a star .... 1 star = none, 2 stars = a little, 3 stars = some, 4 stars = a lot

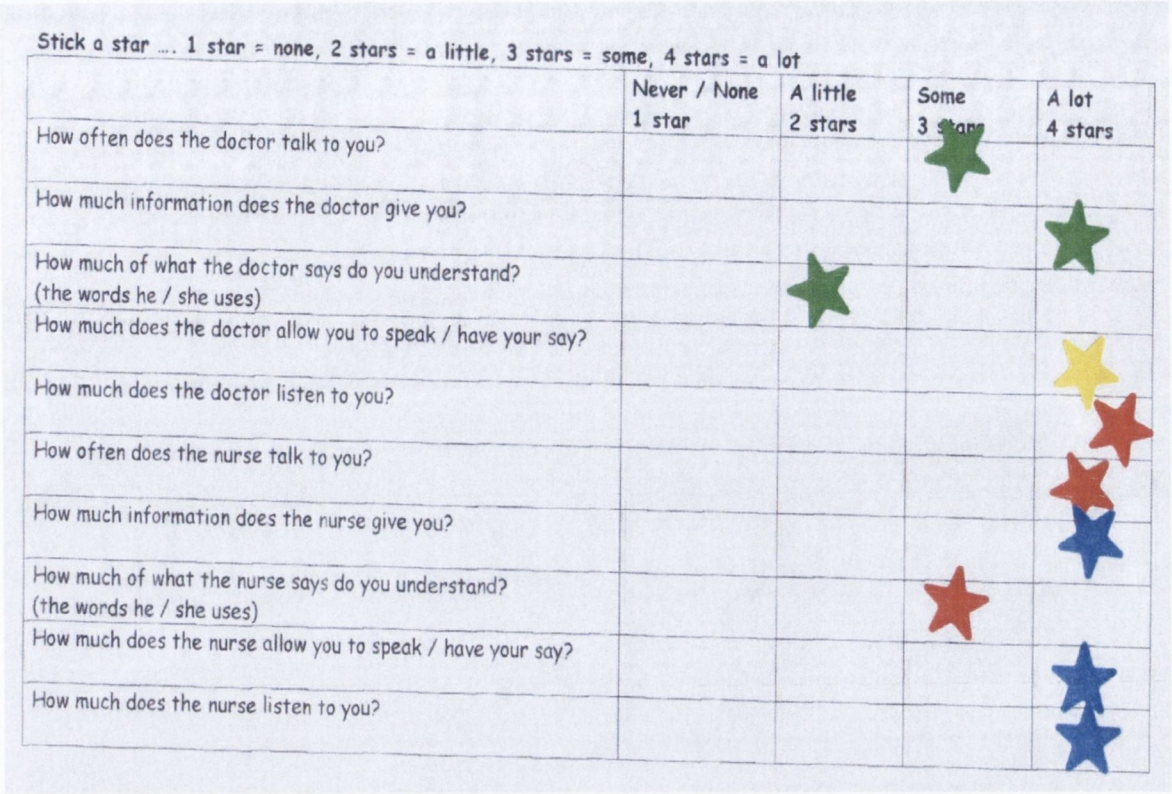
| | Never / None 1 star | A little 2 stars | Some 3 stars | A lot 4 stars |
|---|---|---|---|---|
| How often does the doctor talk to you? | | | | |
| How much information does the doctor give you? | | | | |
| How much of what the doctor says do you understand? (the words he / she uses) | | | | |
| How much does the doctor allow you to speak / have your say? | | | | |
| How much does the doctor listen to you? | | | | |
| How much does the nurse talk to you? | | | | |
| How much information does the nurse give you? | | | | |
| How much of what the nurse says do you understand? (the words he / she uses) | | | | |
| How much does the nurse allow you to speak / have your say? | | | | |
| How much does the nurse listen to you? | | | | |

In this study certain communication skills used by health professionals, namely open ended questions, resulted in children's increased involvement and encouraged the expression of children's views. Open-ended questions usually begin with, 'what, why, could, how', and request an answer of perception, information or feelings (Petrie, 1997; Roter, 2002). Such questions invite children into the conversation at a more participative level than closed questions. They bestow on children the opportunity to talk freely about their experiences, things of interest or importance to them, as opposed to things of interest or importance to the health professional's agenda. This brings children and their agenda, to the forefront of the communication process. For instance, Joanne described the consultant who had reviewed her, following her admission to the children's ward, as "sound", because he gave her an opportunity to talk about what she remembered about what had happened to her before she was admitted. I also observed this some time later when Joanne's consultant came to see her.

> Joanne sat up on her bed. The consultant and two other doctors entered the room and approached Joanne's bed. The consultant stood at the foot of the bed with the two other doctors next to her. A Clinical Nurse Specialist stood next to them. A staff nurse entered the room and joined the team at the end of Joanne's bed. Joanne's mother was not present.
> Consultant to Joanne: Joanne, what happened? Joanne: I don't know.
> The consultant turned to the two doctors: I know Joanne well, so just tell me the history about coming in this time. The two doctors went through what had happened Joanne on Saturday before she came to hospital.
> (Field Notes: Observation: Joanne 14 years: January 2005)

Orla expressed a similar view when completing her stick-a-star quiz, illustrated below (stick-a-star quiz 6). In response to the question, how much does the doctor allow you to speak/have your say, Orla stated the doctor gave her a lot of say (four stars) when he asked her openly about her seizures and what had happened. This illustrates a two way interaction, whereby Orla was *"invited into the conversation"*, thus placed at the forefront of the communication process, by being given an opportunity to tell her story about what had happened.

**Stick-a-Star Quiz 6: By Orla 10 years: January 2005**




In this next scene, taken from my observational field notes, the physiotherapist employed an open, yet structured and sequenced, approach to elicit information from Gavin. For example, the physiotherapist asked Gavin, can you tell me what happened yesterday when you woke up? This was followed by the question, what happened then after you got up? In doing this the physiotherapist attempted to take Gavin through an account of what had happened, stage by stage. This assisted in inviting Gavin into the conversation and bringing him to the forefront of the communication process, because it provided concrete time markers to stimulate Gavin's memory.

> Physiotherapist to Gavin: You were playing hurling and got hit, were you messing or playing a game (kneeling on floor leaned slightly forward and talked in a calm slow voice)
> Gavin: My friend hit me
> Physiotherapist: Your friend....was it an accident?
> Gavin: No..
> Physiotherapist: Did he say sorry?
> Gavin: No..
> Physiotherapist: Where exactly did he hit you ....could you show me?
> Gavin pointed to where he was hit on his leg.

Physiotherapist: Is it here in this place on your other leg…(looking at the good leg)
Gavin: (head nodded yes)
Physiotherapist: Can I see this leg now …I'll touch… feel it only gently (touching leg)…okay can you tell me what happened yesterday when you woke you?
Brief silence
Physiotherapist: What time did you wake up at?
Gavin: I don't know….
Physiotherapist: That's okay I'll check with your mum for that one …what happened then after you got up…did you walk or were you able to stand?
Dad to Gavin: You told the doctor yesterday you were able to take a few steps then crawled.
Dad to physiotherapist: When he arrived into their room …he crawled in and I thought he was messing when he said he couldn't walk
After a few minutes the physiotherapist got Gavin to lie down and did some exercises with his legs. She got him to push against her hand and then she would push against him. Gavin was now smiling and laughing.
Physiotherapist to Gavin: Have you any brothers and sisters?
Gavin: Two sisters
Physiotherapist: I guess their names are (name) and (name)
Gavin: No ….(Gavin told the physiotherapist his sisters names)
Physiotherapist: And do you love them?
Gavin: (Smiling)
Dad: (Laughing)
(Field Notes: Observation: Gavin 6 years: February 2005)

Similarly, the following observation illustrates, a staff nurse verbally and non-verbally, through her posture, placing Emily at the forefront of the communication process.

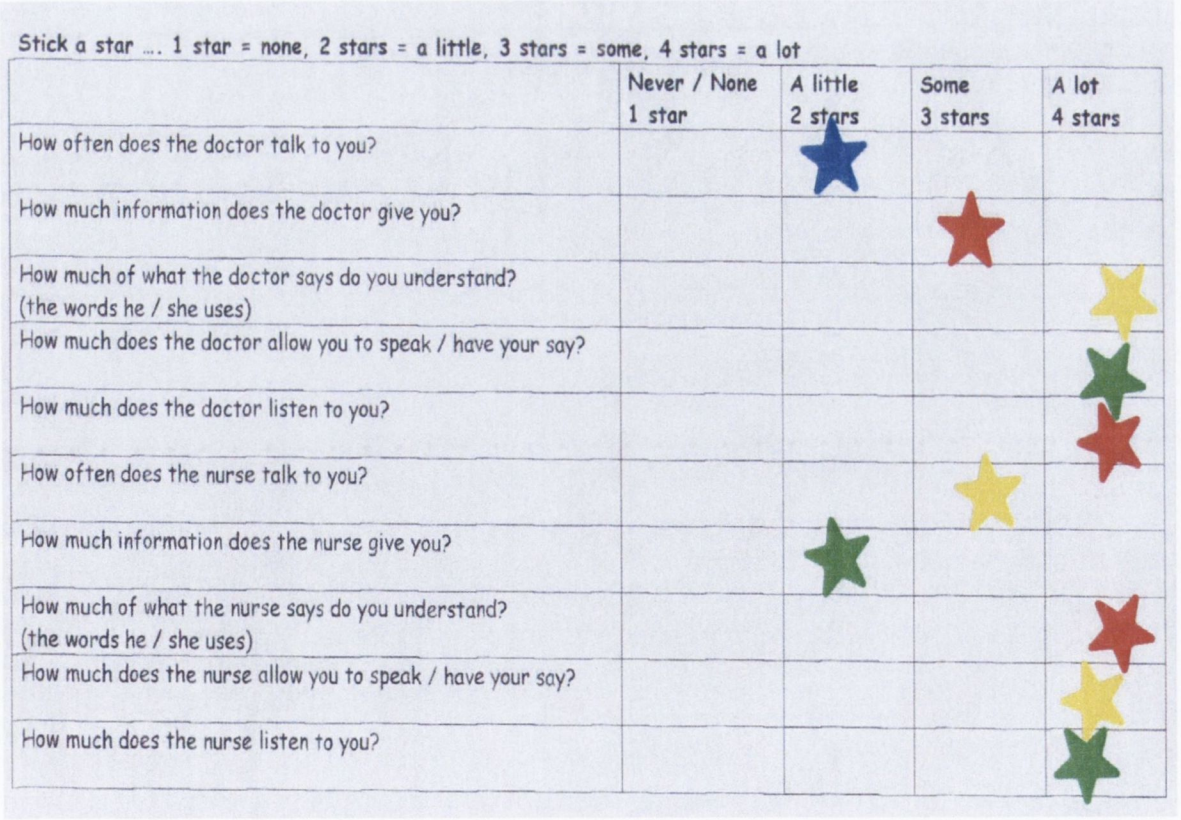
Emily was sitting on a chair at the end of her bed. A staff nurse entered the room and approached Emily. She got down on her hunkers beside Emily.
Staff nurse to Emily: How is your arm?
Emily: I think I need an x-ray
Staff nurse: Why do you think that?
Emily: Because my arm is sore here (pointing to IV)
Staff nurse: Does it hurt when I press it?
Emily: No
Staff nurse: Well I don't think you need an x-ray …what we might have to do is to take that one (pointing to IV) out and put it in the other arm.
Emily: Put it in this arm
Staff nurse: Yes….not yet …I'll put more water in it later and see how it is.
(Field Notes: Observation: Emily 7 years: December 2004)

In the extract above, the staff nurse bent down to Emily's level to talk with her, inquiring openly how her arm was. This afforded Emily with an opportunity to express her view about what was wrong with her arm. Emily interestingly stated she thought she needed an x-ray. The staff nurse listened to and responded to Emily by exploring further why Emily thought she needed an x-ray. This exposed the problem that Emily's arm was sore. Then

a possible solution was presented by the staff nurse to Emily. In this instance, the staff nurse demonstrated interest in Emily by attempting, through open exploration, to understand Emily's thoughts and perceptions, in addition to, attentively listening, acknowledging and encouraging further elaboration of Emily's views. In doing this, the staff nurse placed Emily's views, rather than those of the health professional, foremost.

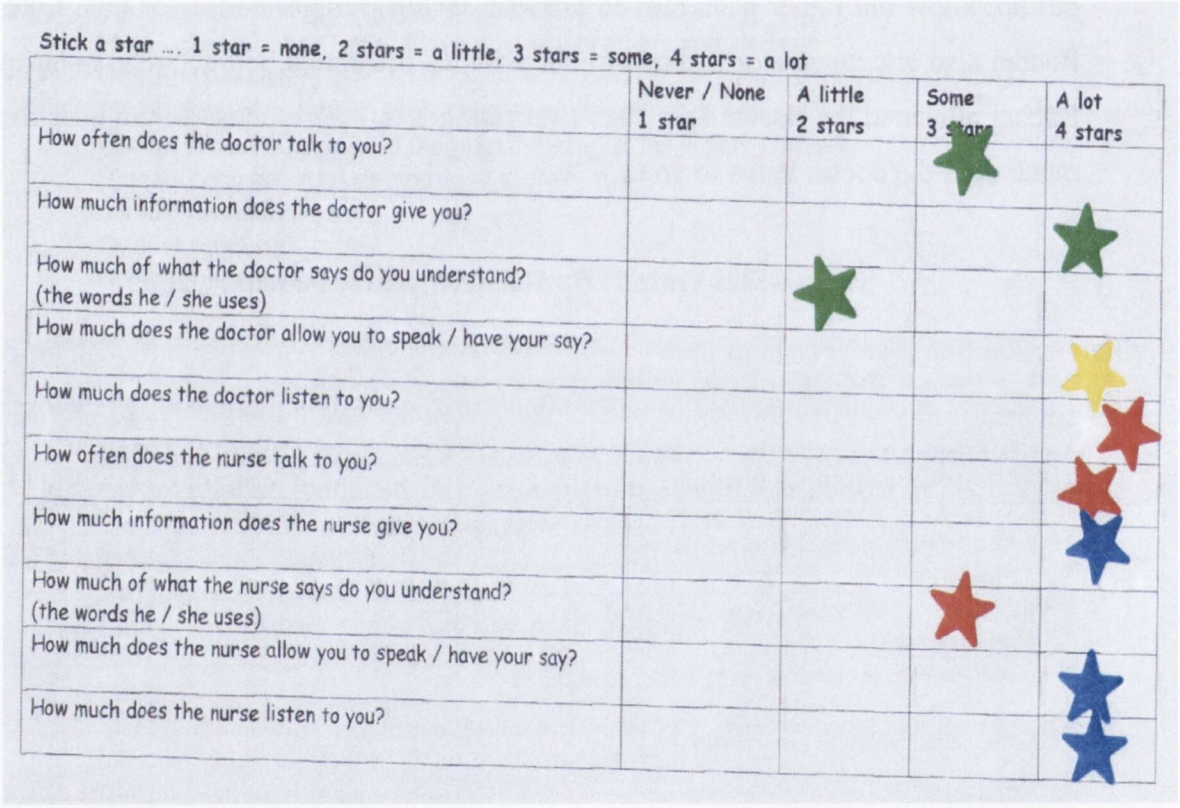
During an informal conversation, Rory (12 years) also highlighted the importance of health professionals actively listening. Rory informed me that the doctor actively listened to him when he was talking because he did not keep talking and did not tell him that he did not know but rather gave him an answer; saying it might be this or this. Like Rory, Rachel also felt the doctor listened to her a lot, as illustrated below (stick-a-star quiz 7). Rachel allocated the doctor four stars (indicating a lot) in response to the question, how much does the doctor listen to you.

**Stick-a-Star Quiz 7: By Rachel 9 years: February 2005**



Rachel relayed to me that the doctor had portrayed to her non-verbally, through his gaze that he was listening, interested in and focusing on what she was saying because he would look at her and talk to her directly and not to her mother or father. This illustrates elements of an encouraging listener, who looks at the other person when they are talking, faces them, gets down to their level, and lets them know they are listening (Petrie, 1997). Orla also demonstrated this in her stick-a-star quiz when she allocated the doctor "four stars", for listening to her a lot, as illustrated below (stick-a-star quiz 8).

**Stick-a-Star Quiz 8: By Orla 10 years: January 2005**




Orla felt the doctor had listened to her because when she was telling him about her epilepsy he would say, "that's okay, that's understandable and all". Here, Orla identified that the doctor employed a longer encouraging response to portray to her that he had actively listened to and heard what she had said. By doing this, the doctor acknowledged and validated Orla's concerns. Petrie (1997) highlighted that when one actively listens carefully to another, the other realises that you are genuinely interested in them, their experiences and you respect what they have to say. This provides positive feedback to the

other person encouraging them to talk and shows active interest in their views. Furthermore, as Hayes et al (2004) proposed the first step in effectively communicating with children is to understand the child's point of view, with listening being a vital prerequisite to this understanding.

While Katie (12 years), a regular attendee to the children's ward, felt she was more involved and asked her opinion more as she got older; older age as an influential factor in determining the degree to which children were involved in the communication process could not be regarded as a universal factor. This is supported by some of the above extracts from my ethnographic field notes which illustrate that younger children, some with no previous hospital experience, were also *"invited into the conversation"*. Furthermore, being of an older age, or a regular attendee to the children's ward, did not necessarily mean that these children wanted to occupy the frontal position of the communication process, all of the time. This is illustrated in the following extract from my conversational field notes, where Katie expressed difficulty with being placed at the forefront of the communication process.

> Katie informed me that the doctor thinks when she finishes her antibiotic she'll [doctor] bring her [Katie] for an operation....they [doctors] asked Katie what she thought about having it [operation] but Katie relayed to me that she didn't know what she wanted. Katie stated that the doctor had only mentioned this to her...no one else...and the last time [she had an operation] the doctor did not ask Katie's opinion....rather she [Katie] was just booked in and had it done. (Field Notes: Informal Conversation: Katie 12 years: January 2005)

In the excerpt above, Katie relayed that at that particular point in time, for that particular issue, she was not ready to be placed at the forefront of the communication process. On a previous occasion, when she was not asked her opinion, Katie found it easier to cope because the decision was already made for her. Perhaps, Katie still required the support of her parents; indicated by the fact that when the consultant informed Katie about the possibility of going to theatre she went to phone her parents straight away. Sometimes children might prefer to occupy the background position of the communication process and value the support of their parents. Katie's fear of anaesthesia could have accounted for her inability to express her opinion about having to have an operation. This is illustrated in the field note extract below, recorded following a further informal

conversation with Katie, when she revealed to me that she was reluctant to disclose, to her consultant, how she truly felt because she feared a negative consequence; which was that her consultant would want to bring her to theatre. Katie revealed the real crux of the problem; she hated undergoing anaesthesia.

> Katie relayed to me that although she felt worse than when she first came into the hospital she was not going to tell her consultant how she really felt. This was because Katie believed if she told the consultant how bad she really felt that the consultant would only bring her to theatre. Katie stressed that she hated theatre "I hate theatre....everyone hates something…I hate been put to sleep". (Field Notes: Informal Conversation: Katie 12 years: January 2005)

Perhaps if Katie's fears and concerns, that she hated being "put to sleep", had been known at the outset, the consultant may have handled the situation differently. This finding has implications for recommending that "all" children should be directly consulted with "at all times". Children themselves should be involved in determining their own level of involvement in the communication process. There may be times and situations when children prefer to remain in the background of the communication process, and other times when these same children wish to occupy a frontal position. For example, as illustrated above Katie was perhaps not ready to be placed at the forefront of the communication by the consultant, at that particular point in time, or for that particular decision. Contrastingly at another particular point in time, illustrated in this next observational field note extract, Katie moved herself to the frontal position of the communication process by self-initiating an interaction with the Cystic Fibrosis Clinical Nurse Specialist (CF CNS) on the ward corridor.

> Katie called after the CF CNS as she walked along the corridor.
> Katie: My port-a-caths not working
> CF CNS: (stopped and turned around to face Katie) What's wrong with it?
> Katie: Don't know (name of staff nurse) and (name of staff nurse) tried it last night but couldn't get it working….they took out the needle it was bent…they said they'd give it a break (pulled her top over a little to expose skin where port-a-cath was)…so they put this in (pointed to peripheral IV cannula)…. I hope it lasts till tomorrow…till I go home. (Field Notes: Observation: Katie 12 years: January 2005)

Other children also actively influenced their own level of participation in the communication process when they initiated interactions with health professionals or 'butted in' to interactions, which took place between their parent(s) and health

professional. For example, Helen informed me she would often start a conversation with the nurses; this would mostly happen in the nurses' station and the topic of discussion would be mainly social. Ciara (13 years) was also very self-initiated in approaching health professionals. I observed her frequently moving to the corridor to initiate conversations with the nurses. She asked them about going home, when the doctor was coming and went in pursuit of a new plaster for her intravenous cannula.

It could be surmised that children who were older and regular attendees, thus potentially more confident and more familiar with the surroundings and health professionals, would be more likely to actively influence their own level of involvement. However, this was not always the case. A number of younger children with no previous exposure to the hospital setting also instigated strategies to actively make their presence known.

One strategy adopted by children in an attempt to bring themselves, and their agenda, to the forefront of the communication process was to 'butt in' to interactions taking place between health professionals and their parents. For instance, Brian (10 years) informed me that he sometimes interrupted when his parents and the doctor were conversing. This point is further illustrated in the following observational excerpt when the doctor came to review Ann. Initially the doctor initiated the conversation with Ann's mother before proceeding to communicate with Ann, for the purpose of examination. At a later point in the interaction, Ann interrupted when her mother and the doctor were speaking. By doing this, Ann got to voice what her concerns were.

> The doctor arrived at Ann's bed and introduced herself to Ann's mother who was sitting on the bed. Ann was standing near the end of her bed. After a brief introduction to Ann's mother the doctor turned to Ann and said…how are you? can you sit over here for me. Ann moved to sit on the chair indicated by the doctor. The doctor reached behind Ann to get equipment from the wall to check Ann's eyes. The doctor sat on the bed opposite to the child's mum and in front of the child who was now sitting on a chair as requested by the doctor. The doctor examined Ann's eyes. As the doctor was examining Ann's eyes mum leaned over to ask the doctor about the redness in her daughter's eyes. The doctor turned her head in mum's direction and responded saying: the redness will last for about 10 days. Next Ann butted in saying that her eyes were sore. The doctor told Ann that her eyes would be sore for a few days. Then Ann's mother checked with the doctor: I can give paracetamol. Doctor: oh yes. Then Ann's mother asked the doctor about Ann's glasses whether Ann needed to wear them. (Field Notes: Observation: Ann 8 years: January 2005)

Similarly, in the next observational excerpt, while the interaction was initiated by a staff nurse with Ann's mother, Ann 'butted in'. In doing so, Ann changed the topic of the conversation and raised an issue of concern for her. This changed the direction of the conversation with staff nurse now focusing her attention towards Ann.

> A staff nurse entered the room carrying a chart which she was reading.
> Staff nurse to mum: So what did the doctor say about Ann?
> Mum: She can go home and come back to the clinic in two weeks ….is it you I see about the appointment.
> Staff nurse: Oh I see it here now (looking at the chart)
> Mum: She (Ann) also has to get ointment
> Staff nurse: She (doctor) never did the prescription
> Mum: She did…she (doctor) gave it to me
> Staff nurse: She's (doctor) on the ball so
> Ann to staff nurse: What about these things…who will take them off? (pulling out T-shirt to show ECG dots on her chest)
> Staff nurse to Ann: Ya they're just sticky you can pull them off …do you want me to do it?
> Ann: Will it hurt?
> Staff nurse: No (scrunching up her nose)
> The staff nurse proceeded to pull the first EEG dot off, Ann watched closely.
> Staff nurse: Do you have another one? Do you want to take that one off?
> Ann removed the second EEG dot and then showed the staff nurse her IV cannula
> Ann: what about this?
> Staff nurse: I'll take it out in a minute.
> The staff nurse left the room.
> (Field Notes: Observation: Ann 8 years: January 2005)

In the following scene from my observational field notes, Freddie also interjects into the interaction taking place between the doctor and his mother.

> A female doctor entered the room while I was there chatting to Freddie. The doctor stood just inside the room cubicle door. Freddie was in his bed. Freddie's mum was on sitting on an armchair beside his bed.
> Doctor to Mother: I want to get the blood tests repeated next week… here in the hospital. Then you will be able to contact your GP as they will send the results there.
> Freddie's mother: Well the GP is away for the next few weeks anyway.
> Doctor to Mother: Well you could ring the hospital and ask to get through to me…I'm (name of consultant) registrar.
> Freddie butted in: Does that mean I can go home today?
> Doctor to Freddie: Yes
> Freddie: Yes (loud happy scream & punched the air)
> Mother: Does that mean this can come out….(pointing to cannula).
> Doctor: Did the ENT doctors want to see him back in clinic?
> Mother: Don't know haven't seen any one from ENT since we came in
> Freddie: A doctor came yesterday ….ENT
> Mother: No that was medical doctor not ENT...

Freddie butted in: How long will I be off school? ...(mouthing Tuesday)
Doctor: Monday..
Freddie: That'll do me.....my mam was going to keep me out of school till then anyway.
Mother: Well could go back on Friday
Doctor: Well the neutrophils are still low and I don't want him to get an infection so keep him away (from school) a few days...
Freddie butted in: Who'll take this out...(pointing to IVC)
Doctor: The nurses
Mother: We don't want to do them (nurses) out of a job...
The doctor then left.
(Field Notes: Observation: Freddie 10 years: November 2004)

The above interaction was initiated by the doctor with Freddie's mother. While the doctor and Freddie's mother conversed, and as no turn was being allocated to Freddie, Freddie interjects asking, does that mean I can go home today? This reshaped the directional flow of the interaction; the doctor now responded to Freddie. Although this brought Freddie to the forefront of the communication process it was only temporary. Next, Freddie's mother interjected to ask the doctor a question.[191] This blocked any further interaction between the doctor and Freddie, because the doctor turned her attention back to Freddie's mother again. Freddie 'butted in' for a second time to ask another question, how long will I be off school? In addition to creating an opportunity to be included and speak, Freddie also changed the topic of the conversation. In doing this, Freddie not only attempted to bring himself to the forefront of the communication process, but also to bring the conversation around to his own agenda, as opposed to the health professional or parent agenda. Thus, two important issues emerge here, wanting inclusion and meeting ones own agenda. For example, Freddie actively sought to be included in the conversation by 'butting in', but he also wanted information to address his own agenda and changed the topic of the conversation to achieve this.

In summary, *"invited into the conversation"* is the first dimension of the conceptual extremity *"being at the forefront"*, which represents one aspect of the *process* of communication and *"visible-ness"* construct. *"Invited into the conversation"* refers to another stance children held within the communication process, that is a frontal position.

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[191] This equates with parents 'butting in' as mentioned in the dimension "standing in background" (section 6.2.2).

In this position, children were placed at the forefront of the communication process by health professionals communicating directly with them, either in their parents' absence or presence. Placing the child actively at the forefront of the communication process and being open to the child's agenda was achieved by giving the child an opportunity to participate in the conversation. It involved exploring, through open questions, the child's agenda and listening actively to what the child had to say. Finally, it afforded the child an opportunity to raise things of importance to him/her by being allocated a turn to ask questions. The consequence of employing these strategies, for children, was that it encouraged and enhanced their active participation in the communication process, in addition to, addressing their agenda. It facilitated a two-way, patient focused, process of communication. Not only did health professionals determine the directional flow of the interaction, children themselves could actively influence their own level of participation by initiating interactions with health professionals or by 'butting in' to interactions taking place between their parent(s) and health professionals, thus determining their own positioning within the communication process. However, in certain situations and at certain times children may prefer to remain passive bystanders, occupying the background overshadowed extremity of the *"visible-ness"* continuum.

### **6.2.4.** Summary: *"Visible-ness"*: Process

To summarise, the communication *process* referred to the degree to which children were directly involved in the communication process, the extent to which the child's agenda was addressed and ultimately governed the extremity of the *"visible-ness"* construct the child predominantly occupied. *Process* linked the two opposing dimensions, *"standing in the background"* and *"invited into the conversation"*, each representing one of the two conceptual extremities of the *"visible-ness"* construct, *"being overshadowed"* and *"being at the forefront"* respectively. The degree to which children were involved in communication process and the extremity of the *"visible-ness"* construct children held was determined by the directional flow of the interaction and the type of communication skills employed by health professionals. Health professionals, parents and children themselves were influential in affecting the directional flow of the interaction process. Listening, questioning and offering reassurance were key communication skills employed

by health professionals which determined, not only the extremity of the *"visible-ness"* construct which the child assumed, but also the extent to which the child was involved and his/her agenda addressed.

In light of previous research, it could be surmised that children of an "older age" (aged 12 – 16years) and those who were "regular attendee's" to the children's ward might be more likely to occupy a frontal position in the communication process, through either being involved more by health professionals or by these children themselves actively influencing their own level of involvement in the communication process. However, it is difficult to draw a conclusive statement on this. There were instances of "younger children" (aged 6-11 years) with "no previous experience" of hospitalisation who were invited into the conversation by health professionals and also some who actively attempted to make their own presence known. There were also instances whereby "older children" (aged 12 – 16 years) were marginalised. Furthermore, being of an "older age" and a "regular attendee" does not mean that these children want to ultimately occupy a frontal position in the communication process at all times. These findings highlight the difficulty with explicitly applying "age" as a criterion for which to determine the child's level of involvement in the communication process.

### 6.3. *"Visible-ness"*: Message

#### **6.3.1.** Introduction

An important objective of the communication process is the transmission of a *message* in a clear comprehensible format from one person to another (sender to receiver and *vice versa*). This section describes the *message* that was exchanged between health professional and child during the interaction *process* outlined above. In this study, the information exchanged and its comprehension constitute the *message* of the communication process. The type, amount and format of information, who exchanged the information, and the level of the child's understanding and interpretation of the information exchanged, ultimately determined the extremity of the *"visible-ness"*

construct which the child assumed.[192] The *message* is comprised of the two opposing dimensions *"left in the dark"* and *"being informed"*, each of which represents one of the two conceptual extremities of the *"visible-ness"* construct, as illustrated below (Figure 10).

**Figure 10: *"Visible-ness"*: Message**



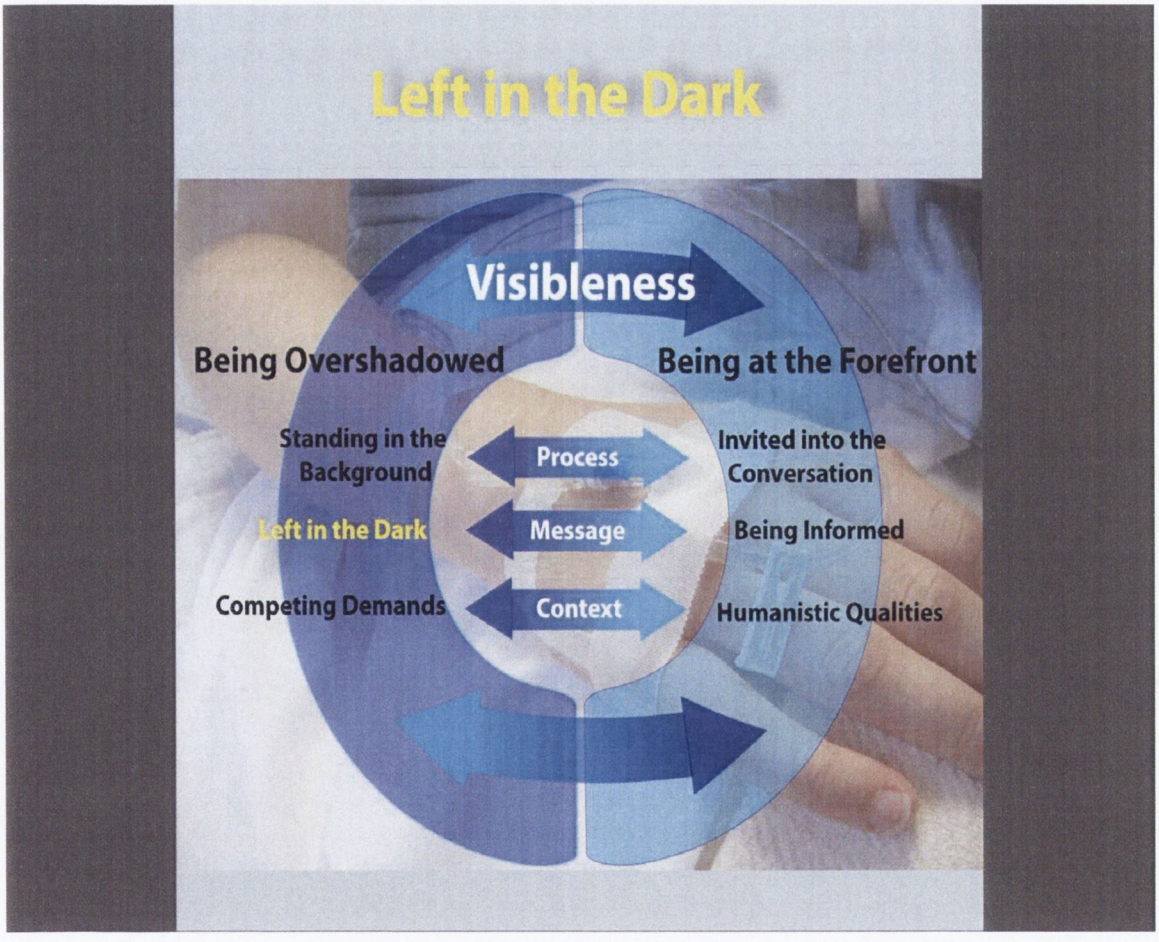

**6.3.2.** "Left in the dark"

*"Left in the dark"* is the second dimension of the conceptual extremity *"being overshadowed"*, which represents one side of the *"visible-ness"* construct, illustrated below (Figure 11). *"Left in the dark"* also constitutes one aspect of the *"message"* of the communication process. This dimension refers to, firstly, children being inadequately or

[192] This is, whether the child occupied the *"being overshadowed"* or the *"being at the forefront"* extremity of the *"visible-ness"* construct.

uninformed about what was wrong with them, what was happening or what to expect in relation to hospital and their illness. Secondly, it refers to children being unable to understand the *message* conveyed because of the use of incomprehensible 'medical' terminology. Because of receiving insufficient and incomprehensible information, children often felt unprepared, wondered, and worried about what was going to happen. In such instances, children were *"left in the dark"*, overshadowed because the process of information exchange was controlled by, and focused on the health professional's agenda, as opposed to the child's agenda. Children expressed a strong desire for in-depth, timely, clear and trustworthy information.

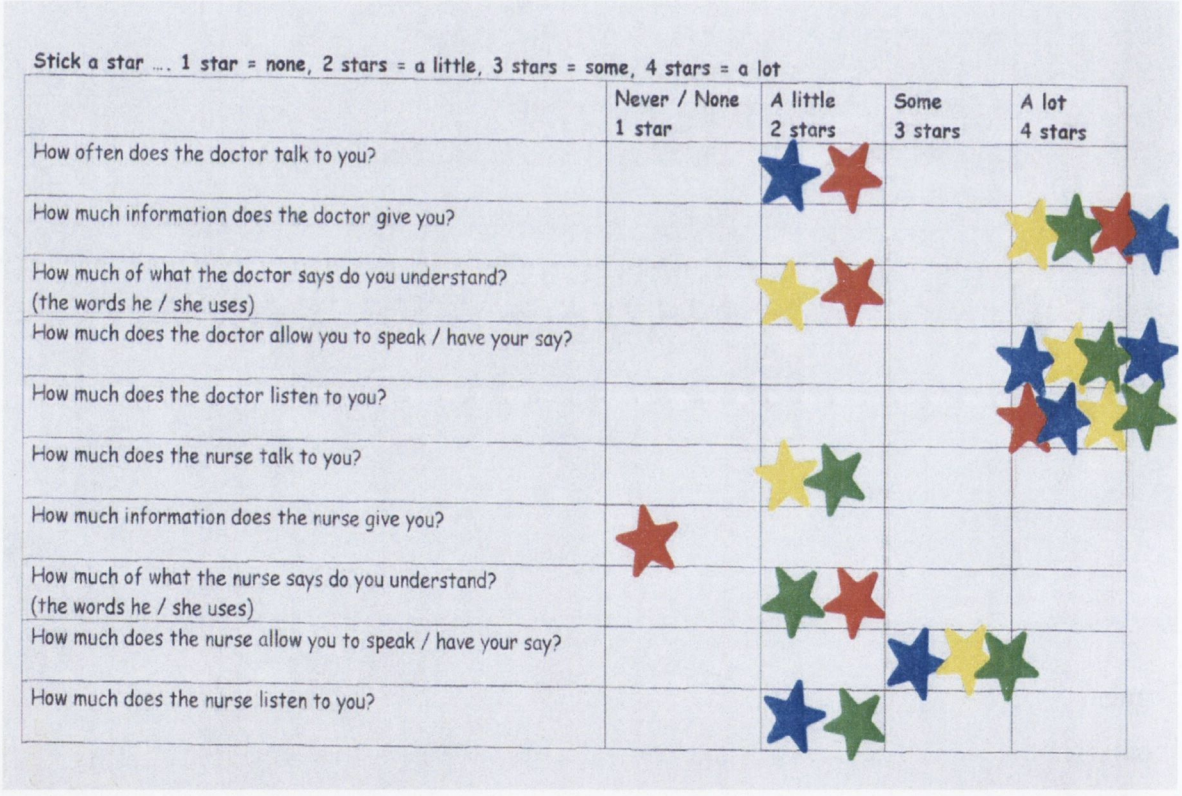
**Figure 11: Dimension *"Left in the dark"***




A number of children reported times when they felt uninformed about their illness or about what health professionals were doing. For example, during an informal

conversation Sinead (9 years) told me that no one really told her about her sickness. She felt someone should have told her about it. This is further illustrated below on stick-a-star quiz 9, completed by Rosie. In response to the question, how much information does the nurse give you? Rosie stated "none" and allocated the nurse "one star" accordingly. On further exploration with Rosie to ascertain if she understood what the word information meant, she responded yes and pointing to all the monitors and equipment around her, including the oxygen attached to her, she stated the nurses did not tell her anything about these. Rebecca (11 years) also relayed that nurses often did not tell her what they were doing. Instead, they [nurses] would just say, "can I put this [oxygen saturation probe] on your finger?"

**Stick-a-Star Quiz 9: By Rosie 11 years: February 2005**

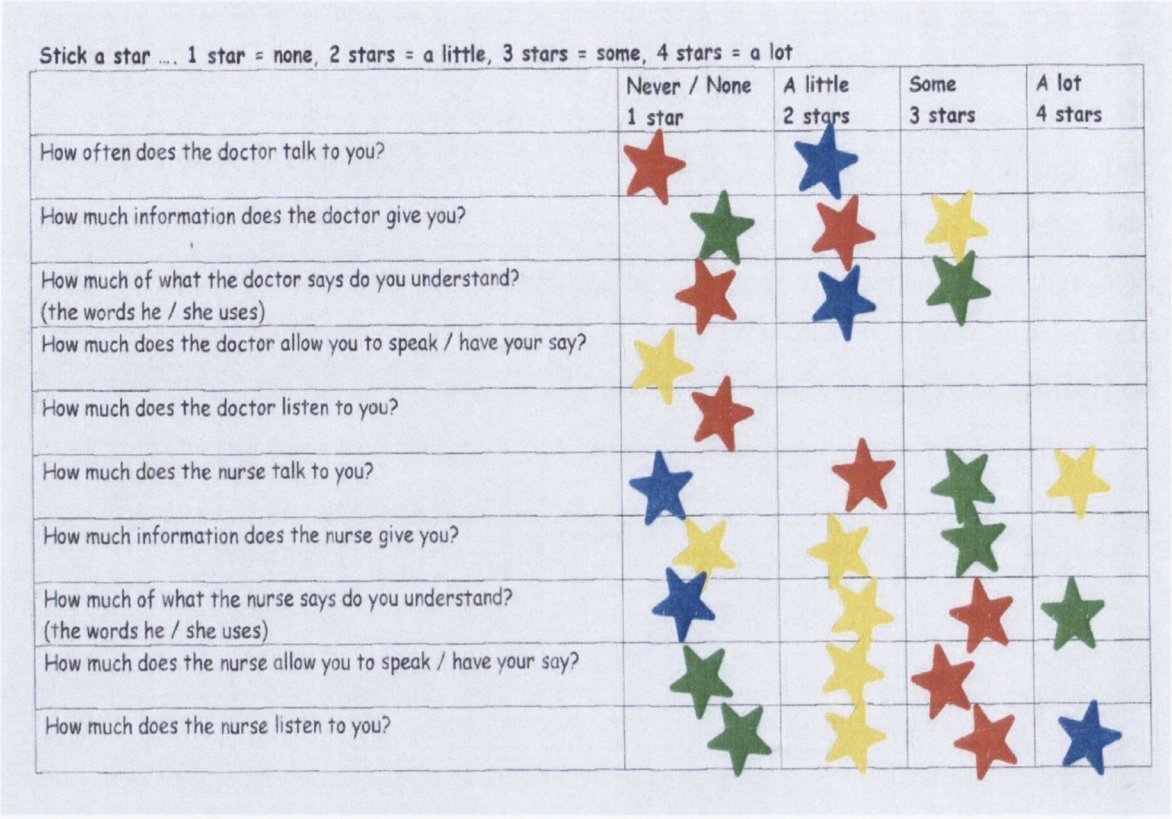



Similar findings were reported by Kilkelly and Donnelly (2006). Consistent with previous research (Van Dulmen, 1998; Beresford and Sloper, 2003), the majority of children who reported receiving inadequate information, by both doctors and nurses, were

in the age range 6-11 years. Possibly, one reason why younger children were insufficiently informed was because information tended to be relayed to their parents. For instance, both Collette (6 years) and Brain (10 years) told me that the doctor did not tell them directly about what was wrong with them, but instead spoke to their parents. While this resembles the interaction *process* as described previously, it is not the same. In the previous *process* Section 6.2, the flow of the interaction was often in the direction of the parent, but it was also sometimes in the direction of the child. However, the main purpose of the health professional interacting with the child was to seek information; through open or closed questioning. This inequity in the way information flows, this is, that children are relied upon for gathering information, whereas information is primarily fed back to their parents, has previously been reported in the literature (Pantell et al, 1982; VanDulmen, 1998). Rachel (9 years) highlighted this when she relayed to me her belief that nurses did not give her information but rather just asked her about her pain.

Other children relayed that although they had received some information, the amount of information they received was insufficient and superficial in nature. For example, when completing the stick-a-star quiz, displayed below (stick-a-star quiz 10), Mary awarded the doctor "three stars" for supplying her with some information. The doctor had told Mary that she would need to have her appendix taken out in five weeks and this meant that she would have to come into hospital again. Probing further with Mary why she only allocated three stars to the doctor for the information he gave her, Mary stated that to award the doctor four stars she would have needed to receive more information about what they [doctors] were going to do when she went down to theatre and also some indication of when she could go home.

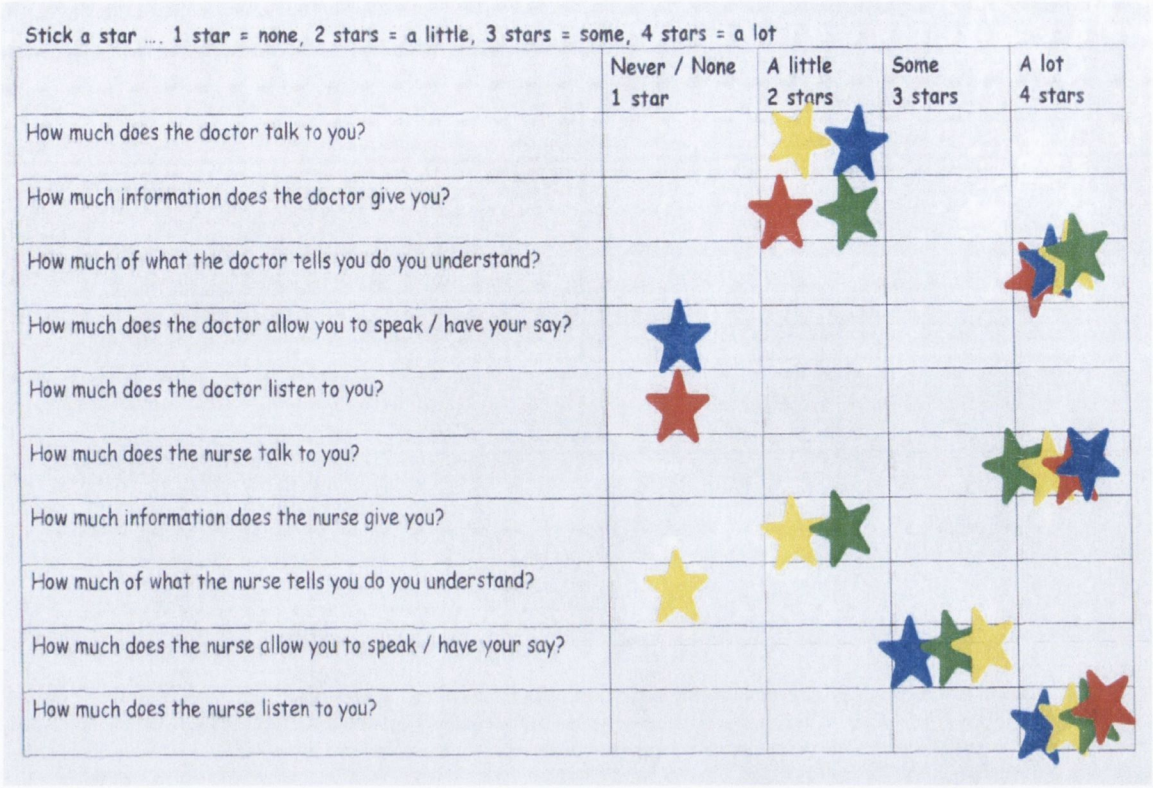
**Stick-a-Star Quiz 10: By Mary 8 years: January 2005**




Similarly, in her stick-a-star quiz, illustrated below (stick-a-star quiz 11), Sinead allocated the doctor "two stars" for providing her with limited information. Sinead stated the doctor told her that she was going to have her appendix taken out and that she could not eat or drink. To be awarded four stars the doctor would have had to provide Sinead with more information about the operation, what he was going to do and what was going to happen. Supplying children with superficial information meant that they were communicated with in a stereotypical way, rather than on a personal individualised basis. For example, children going for surgery automatically received customary information, such as, they needed to have an operation and they would be asleep for this operation.[193]

[193] Walters and Coad (2006) also identified the need for more specific information as opposed to generalised information for children undergoing spinal surgery.

**Stick-a-Star Quiz 11: By Sinead 9 years: January 2005**




This superficial approach to information provision fails to identify and address children's individual concerns and worries. For instance, despite being told that he would be asleep for his operation, during informal conversation Denzel informed me that he was still scared, fearing the pain he would experience after the operation, illustrated in the extract below.

> Veronica: How do you feel about maybe having to have an operation?
> Denzel: Well they put you asleep but still, a bit scared
> Veronica: Scared, how come?
> Denzel: Because it will be sorer afterwards
> (Field Notes: Informal Conversation: Denzel 10 years: February 2005)

Collette (6 years) and Stephen (11 years) expressed similar concerns during informal conversations. They were both nervous about their operation but could not pinpoint any one thing in particular that they were nervous about. Collette told me she was nervous because she had never had an operation before and she was scared because she did not

know what it would be like. While it is quite natural to experience fear of the unknown when facing an uncertain situation, it is also essential to assist children to cope with and dispel their fears. Receiving insufficient superficial information meant children were unprepared for future events. For example, Luke was not informed pre-operatively about the possibility of having a wound drain post-operatively.

> I asked Luke if he knew he was going to have the wound drain after his operation. Luke stated, no he thought he would only have bandages. He went onto say that he didn't know what it [drain] was when he saw it [drain] when he woke up [after his operation]. He said at first he thought that the blood in the tube was going into him, that he was getting blood. He didn't know it was his blood that was coming out. (Field Notes: Informal Conversation: Luke 11 years: February 2005)

Similarly, Mary spoke about waking up after her surgery with various "things" attached to her. Mary did not know what these "things" were for.

> Veronica: Did you go to the theatre?
> Mary: Yes but I didn't have my operation yet
> Veronica: So, what happened in the theatre?
> Mary: They put these three things on (pointing to ECG dots on her chest) and a mask here (hand to face) and a drip thing here (pointing to her hand).
> Veronica: Do you know what they are all for?
> Mary: No
> Veronica: Did anyone tell you what they were for?
> Mary: No
> (Field Notes: Informal Conversation: Mary 8 years: January 2005)

Ann and Jodie expressed similar sentiments to me the morning after their surgery.

> Ann said to me, I'll show you what they put here. Ann held out her top to show me ECG dots on her chest and pointed to an IV cannula in her hand.
> (Field Notes: Informal Conversation: Ann 8 years: January 2005)

> Jodie informed me that she was not told that she was going to get "that" (pointing to her IV cannula). She said she just woke up with it. She had gotten it down in theatre. I asked her what it was for, she responded saying she didn't know. Then she said the nurses put water in it, with like a needle. Jodie stated "they [nurses] tell me its water to make me better". (Field Notes: Informal Conversation: Jodie 9 years: November 2004)

The consequence, for children, of not being prepared was that they often wondered and worried about what would happen. For example, when I asked Ann what was going to happen when she went for her eye operation, she illustrated her uncertainty in her

response to me saying, they [health professionals] put you asleep I think, do they? Ann wondered: do they cut your eye open? My mam said they don't, do they?" Furthermore, misconceptions may prevail, as illustrated in the following encounter with Denzel.

> Denzel asked me, is it true that you need your appendix to eat grass? He said, "the girl" (another patient aged 9 years) "over there" (in opposite bed to Denzel) told him. The girl had told him that her teacher had told her. Denzel then stated he had asked a nurse this too and the nurse had just laughed. (Field Notes: Informal Conversation: Denzel 10 years: February 2005)

The above examples portray uncertainties experienced by children, indicating their need for informative reassurance. These findings support other studies which have also reported children's fear of the unknown and lack of information provision (Coyne, 2006; Coyne and Conlon, 2007). Providing children with adequate information would assist in alleviating some of the anxieties experienced by these children as they wondered and worried about what would happen next (Stevenson, Grieves and Stein-Parbury, 2004; Gibson et al, 2005). Not only did children clearly articulate that they wanted more in-depth information, they also emphasised the importance of receiving timely and trustworthy information, as illustrated in the field note excerpts below; recorded following informal conversations with a number of children.

> Mike told me that the anaesthetist came the night before his operation on his spine to tell them [his parents and him] about blood coming out at one side of body into a machine and then going back in another side. Mike relayed that he thought telling them only the night before the operation was very late. (Field Notes: Informal Conversation: Mike 12 years: November 2004)

> Ann described to me what she had been told before her operation. She said the doctors and nurses told her it [operation] wouldn't be sore. Ann went onto highlight that it [operation] was sore. Ann also stated that they [health professionals] told her she might feel sick in "my tummy" after it [operation], but she wasn't. (Field Notes: Informal Conversation: Ann 8 years: January 2005)

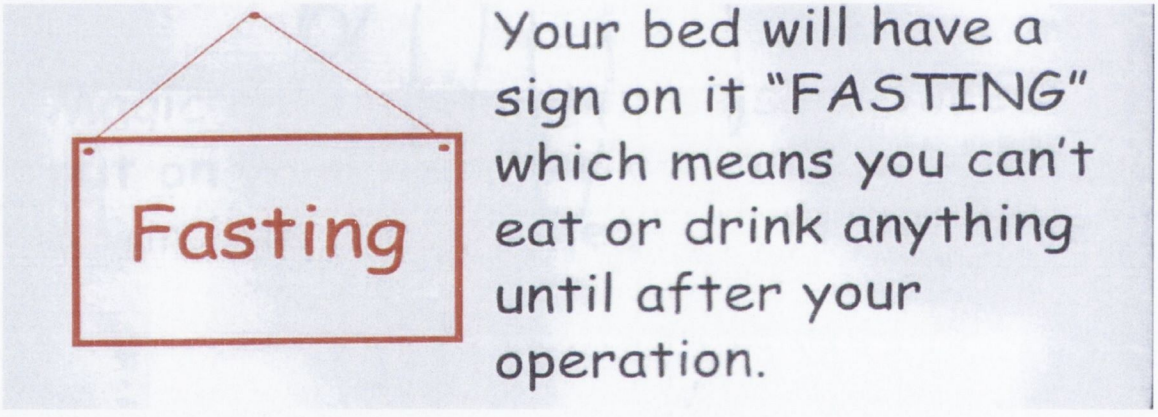
> When talking about having her drain removed Chloe relayed to me that the nurse had told her it wouldn't be sore but Chloe told me it was very sore (Chloe grimaced) and stated for this reason it was good that she was still a bit zonked from the morphine she had gotten after her operation. (Field Notes: Informal Conversation: Chloe 16 years: November 2004)

The provision of adequate, accurate and timely information to children is vital. However, this information must be in an accessible format and easily understood by the child involved. Just less than half of the children talked about times when they did not

understand the "weird" and "big mad words" used by health professionals. For example, Maria (10 years) felt health professionals talked a different "non-English" language. Freddie (10 years) expressed a similar view stating that when he was in casualty the doctors were talking about parotid glands and he was thinking "way hay…can ya talk in English please". The following scenario illustrates that Ann did not understand what the word "fasting" meant.

> Ann relayed to me that she was not allowed to eat or drink because she was having her operation today. Ann proceeded to read aloud from a book that she was given by a nurse the night before, she read "your bed will have a sign on it fasting" (extract from booklet illustrated below). Then Ann stopped reading and pointed to a fasting sign at the top of her bed and said to me, "but I didn't have my operation yet". When I asked Ann what fasting meant she replied that she didn't know. So I asked her, what did the book say? Ann referred back to the book and read aloud "fasting which means you can't eat or drink" (extract from booklet illustrated below). (Field Notes: Informal Conversation: Ann 8 years: January 2005)

**Extract 1: From hospital pre-admission book Ann was reading**




While the majority of children who expressed difficulty with understanding were in the age bracket 6-11 years, some older children, aged 12-16 years, also stated they had difficulty, at times, in understanding the words health professionals used. For instance, Sue (12 years) told me that sometimes the doctors used big words when she needed to go for a blood test such as "gall stones", "like is that your kidneys?" Even Helen, who was a regular attendee to the children's ward, emphasised that she did not always understand new information that she was presented with, as the extract below illustrates.

> Helen stated that even though she is coming in and out a long time to the children's ward and hospital that one might think that she understands everything but she

> highlighted to me that sometimes there are new things that she doesn't understand. (Field Notes: Informal Conversation: Helen 12 years: February 2005)

Rory also drew attention to some words that he did not understand.

> Rory told me that he did not know what the word "pelvis" was when he was first admitted. He said the doctor should have just said hip. Rory went on to highlight that he also didn't initially know what the difference between "fracture" and "broken" was, but now he knew that they are the same thing…and the orthopaedic doctor "that's my bone doctor". (Field Notes: Informal Conversation: Rory 12 years: February 2005)

Interestingly, while conversing informally with some of the children they often adopted medical terminology used by health professionals. However, it soon became apparent that the children lacked understanding of what some of the words meant. This is illustrated in these next field note excerpts recorded following informal conversations with Mary and Sean.

> Veronica: You said about having to have your appendix out in five weeks and not now….how come?
> Mary: Because there is a mass around it [appendix]
> Veronica: A mass …what's that?
> Mary: Don't know….but they have to get rid of it [mass] first then they can take out my appendix.
> (Field Notes: Informal Conversation: Mary 8 years: January 2005)

> Veronica: What's that for? (pointing to cream on Sean's arm)
> Sean: It's in case I have to get another one of them (pointing to his IV cannula)…. I had it on for when I got the drip and I didn't feel the needle going in….it's [drip] to stop me getting dehydrated
> Veronica: Dehydrated …what's that?
> Sean: I don't know they just told me
> (Field Notes: Informal Conversation: Sean 10 years: November 2004)

The consequence for children of employing medical terms that they do not understand, is that it could result in health professionals forming false assumptions of children's level of knowledge and understanding. These aforementioned examples mirror Kilkelly and Donnelly's (2006) findings and display how technical language can ultimately lead to ineffective communication. Speakers may employ technical language to assert their status, authority, knowledge, role and power (Bourhis, Roth and MacQueen, 1989; Lee and Garvin, 2003; Henderson, 2003). Beresford and Sloper (2003), exploring the experiences of chronically ill adolescents communicating with health professionals, reported that adolescents viewed the use of medical terminology as a means by which

doctors emphasised their status; preventing them from contributing to the discourse. In this study, Deirdre (12 years) also mentioned this when she told me she was unable to respond to health professionals because she did not understand what they were saying.

Moreover, if children do not understand what is said, this can lead to the misinterpretation of information. This fact was distinctly exposed by Rory who relayed to me that when he was first admitted to the children's ward the doctor had informed him, in his parent's absence, about what was wrong with him. Rory stated that the doctor told him that his pelvis was cracked in three different places and broken in the back. From what the doctor had said, Rory interpreted that his "back was broken". Rory transmitted this information, that he "back was broken", to his father when he arrived to the hospital. This caused his father great concern and anxiety. However, what the doctor had meant was that there was a "break in the back of the pelvis". So although the doctor did provide Rory with information about what was wrong with him, this information was misinterpreted by Rory.

Four important questions emerged from Rory's story. Does the way health professionals transmit information affect children's interpretation? Is children's interpretation associated with their cognitive development? Should health professionals' not seek clarification of children's understanding of the information exchanged? When information is been given to children is it important, and even essential, that their parent's are present? Drawing on the work of Donaldson (1978), an obvious way to interpret the aforementioned scenario, described by Rory, would be to declare that Rory did not understand the doctor. However, Donaldson (1978:17) would further argue that perhaps at a deeper level the doctor failed to understand Rory, because he failed to place himself "imaginatively at the child's point of view". A child might be judged incompetent by an adult simply because the adult does not possess the skill to communicate with the child (Gabe, Olumide and Bury, 2004). Furthermore, Donaldson (1978:18) postulated that the "better you know something, the more risk there is of behaving egocentrically in relation to your knowledge". Health professionals often become so familiar with the everyday routine use of their medical discourse that they do not realise the extent of its

unfamiliarity to their patients (Stevenson, Grieves and Stein-Parbury, 2004). This can act as an exclusionary method inhibiting the patient's ability to understand and respond to what is being said (Sieh and Brentin, 1997). Rory's mother suggested one way to overcome this problem, of children's misinterpretation, was for health professionals to ask the child what he/she has heard, thereby checking the child's interpretation and understanding of what was said. This validation is an important, yet often neglected, [194] part of the trans-circular model of communication, as highlighted in this study by Sue (12 years) when she stated that the doctors did not ask her if she understood. Sharing information is more than merely imparting knowledge, it is a two way process that requires periodically checking how the information imparted was received and understood (Stevenson, Grieves and Stein-Parbury, 2004).

These findings support previous research in which children expressed a strong desire for health professionals to direct clear, honest, accurate and more in-depth information to them.[195] A possible reason why health professionals are reluctant to provide information directly to children is that they view this as parents' responsibility. In previous research, undertaken with children with life threatening illness, parents highlighted that they preferred to receive information first, before their child (Ellis and Leventhal, 1993; Young et al, 2003). This enabled parents to act as gatekeepers and filter the information that was given to their child. Another explanation for why health professionals merely provide children with limited superficial explanations is that it avoids going into the inner complexities of the specific operation or surgical procedure, therefore, avoids the risk of upsetting or overwhelming children by the situation (Bluebond-Langner, 1978; Ellis and Leventhal, 1993; Young et al, 2003). The advantage to such an approach is that it allows information to be given in a timely fashion, but also avoids distressing children by discussing the inner complexities of having surgery. Instead, health professionals attempt to maintain an optimistic perspective. This was evident in this study by the fact that child

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[194] Mordiffi, Tan and Wong (2003) found that only 23% of physicians routinely asked adults patients to reiterate their understanding and Wales et al (2008) reported that only 21% of nursing staff asked parents to repeat their understanding of information relayed.

[195] For example, Elliott and Watson (1996), Chapman et al (2000), Heary (2001), Horstman and Bradding (2002), Boylan (2004), Salter and Stallard (2004)

participants expressed their belief that doctors examined them to make them better and having an operation was to make them better. Additionally, health professionals frequently told children that what they were doing "was to make them better". This has been previously described as "optimistic assertion" (Teasdale, 1989), "assertion of optimism" (Fareed, 1996) and "reflexive reassurance" (Morse et al, 1992). "Optimistic assertion" is similar to, but differs from "false reassurance", in that it is focused on protecting the patient, as opposed to "false reassurance" which is centred on protecting the health professional (Teasdale, 1989; Stevenson, Grieves and Stein-Parbury, 2004). While there may be many plausible explanations for filtering the amount and type of information given to children it neglects children's right to information.

Indeed, a small number of the children preferred to be *"left in the dark".*[196] For example, when asked was it important to be told about what was happening Frank (11 years) stated that he was not particularly bothered once he got better. A possible reason why children may prefer to remain in the background of the communication process is they do not want to hear bad things.[197] For example, in response to the stick-a-star quiz question, how often does the doctor talk to you, Rachel stated a little, which she equated to twice a week, thus allocated the doctor "two stars" accordingly, as illustrated below (stick-a-star quiz 12). However, when probed further about what Rachel thought about the frequency of when the doctor came to see her, Rachel stated twice a week was sufficient. Rachel did not like the doctor coming to see her too often because she got scared about what he would say.

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[196] This equates with Katie's scenario, that perhaps there were times when she did not want to be invited into the conversation but prefered to stand in the background (described under "process" Section 6.2.3). Similarly here, there were times when children preferred not to be informed.

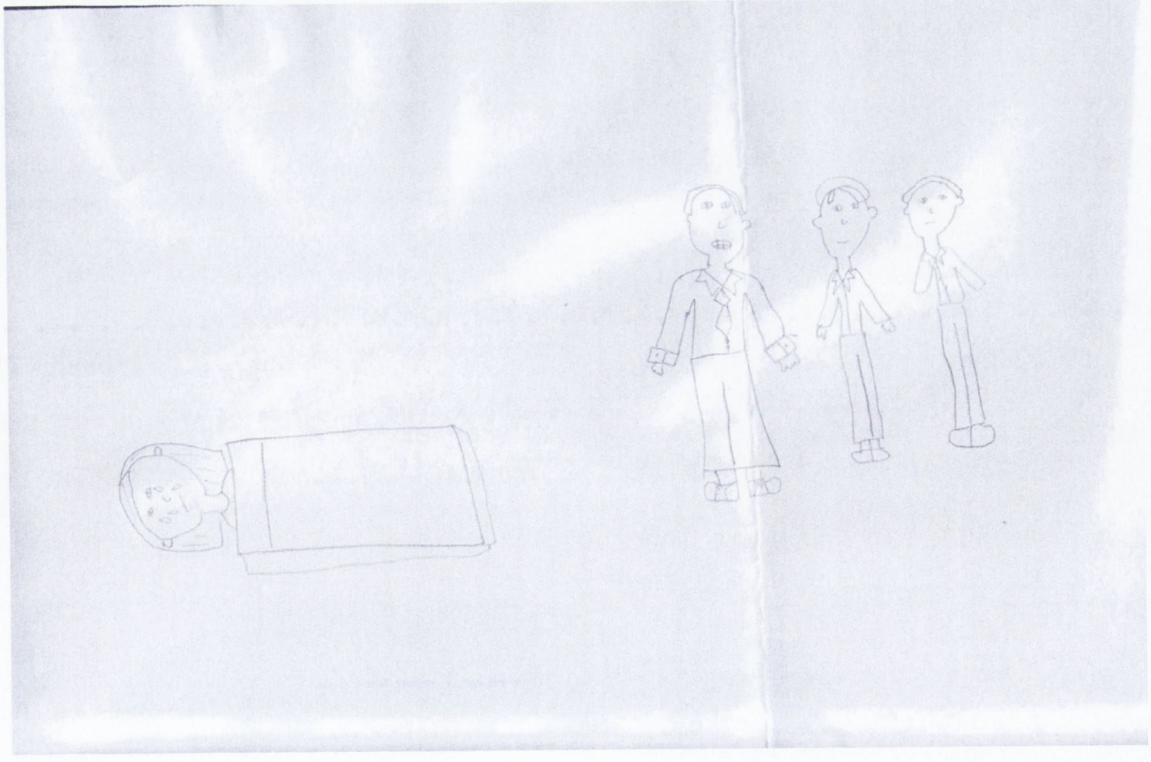
[197] Boylan (2004) and Gibson et al (2005) reported similar findings. Some children preferred not to know everything and some children found information overwhelming and wanted health professionals to ask them if they wanted information at that time.

## Stick-a-Star Quiz 12: By Rachel 9 years: February 2005

Stick a star .... 1 star = none, 2 stars = a little, 3 stars = some, 4 stars = a lot

| | Never / None<br>1 star | A little<br>2 stars | Some<br>3 stars | A lot<br>4 stars |
|---|---|---|---|---|
| How often does the doctor talk to you? | | | | |
| How much information does the doctor give you? | | | | |
| How much of what the doctor says do you understand? (the words he / she uses) | | | | |
| How much does the doctor allow you to speak / have your say? | | | | |
| How much does the doctor listen to you? | | | | |
| How often does the nurse talk to you? | | | | |
| How much information does the nurse give you? | | | | |
| How much of what the nurse says do you understand? (the words he / she uses) | | | | |
| How much does the nurse allow you to speak / have your say? | | | | |
| How much does the nurse listen to you? | | | | |

## Drawing 5: Sinead 9 years (January 2005)



Similarly, in her drawing, displayed above, Sinead depicted how she vividly expressed her feelings, non-verbally, when the doctor came to see her. Sinead drew a girl in bed underneath blankets, right up to her neck. The girl was crying. Sinead stated she was "scared" because the doctor had told her that she had to have an operation, she needed to have her appendix removed.

Collette (6 years) expressed similar sentiments stating that she was "afraid" when the doctor came to see her. Collette relayed that she displayed her fear by turning away from the doctor when he talked to her. Perhaps in these instances, the children preferred to depend on others, such as their parents. Coyne et al (2006) and Lewis et al's (2007) work support these contentions that some children want their parents to protect them and are happy when communication is directed to parents because of the fear of hearing bad news or distressing information.[198]

In the following extract, John highlights how he was overshadowed by his parents when the doctors explained the operation to them and not to him. John did not care that this had happened because he did not really want to be informed anyway.

> Veronica: What were told when you came in about the operation?
> John: Well they [doctors] told my mam and dad about the operation
> Veronica: So the doctors told your parents about the operation …how did you feel about that?
> John: Well…I didn't care…I didn't want to know really…just that they were going to take it [appendix] out …that's all I wanted to know really.....My uncle had his [appendix] out also when he was my age and in this same hospital as well.
> (Field Notes: Informal Conversation: John 13 years: February 2005)

All John wanted to know was that the doctors were going to remove his appendix. This is in direct contrast to those children who reported that merely being informed that they were going to have their appendix removed was insufficient information. One possible explanation for John's view is that John was extremely sick when he was admitted with a

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[198] Children's choice for not wanting to hear bad or distressing information has implications for child's ability to make decisions about their care, thus the direct link here to how communication affects the decision-making process is illuminated.

perforated appendix which required immediate surgery. Another influential factor, as highlighted by John in the excerpt above, could have been the fact that his Uncle had his appendix out at the same hospital when he was John's age. Thus, perhaps to John he viewed this as a routine operation, equating it with his uncle having previously been through it.

Owing to the variability in the amount and type of information children would like to receive it is important to identify what information children want to be given. In doing this, it illustrates what children actually want to know in accordance with their agenda. This differs from health professional led information, which is provided in accordance with what health professionals think children want to know, or perhaps think is reasonable to give children. Children in this study were clearly able to articulate what they wanted to be informed about and what they thought other children coming into hospital should be informed about (see Table 5).

**Table 5: Information Children Want to Know**

| CHILDREN IN HOSPITAL WANT TO KNOW THE ANSWERS TO THE FOLLOWING QUESTIONS | CHILDREN COMING INTO HOSPITAL SHOULD BE INFORMED OF THE FOLLOWING |
|---|---|
| What's wrong with me? | What to bring to hospital? |
| What's happening? | Toothbrush and tooth-paste |
| What are they going to do? | Night-clothes |
| Will it hurt? | Slippers |
| Will I have to get needles? | What things you can do? |
| What's it [hospital] like? | The playroom is a fun place |
| What can I do [in hospital]? | You can get games there [playroom] |
| Are the people nice? | You can go to school |
| How it'll [illness] affect me? | The school teacher comes to the ward |
| Will I get better? | |
| Will I get an operation? | |
| When will I get the operation? | |
| How long will the operation take? | |
| When can I eat [fasting]? | |
| What can I eat [restricted diet]? | |
| What medicine is it? | |
| When can I go home? | |

These findings mirror those reported by Smith and Callery (2005).[199] If children's agenda was to the fore, health professionals and parents could assist children to identify their fears and concerns and gain a more accurate in-depth picture of the child's reaction to impending situations. It would assist in identifying what specific information the child would like to be given. Ultimately, this would result in care that would be truly based on each individual child's needs.

In summary, *"left in the dark"*, is the second dimension of the conceptual extremity *"being overshadowed"*, which represents one aspect of the *"visible-ness"* construct. This dimension, *"left in the dark"*, refers to children receiving inadequate and incomprehensible information, about what was wrong with them, what was happening or what to expect in relation to their hospital stay and illness. These children, who were mostly in the age range 6-11 years, expressed a strong desire for more in-depth, timely, accurate and comprehensible information. Because of receiving insufficient information, children were unprepared and often wondered about what was going to happen. Children were *"left in the dark"* with the process of information exchange focusing on and controlled by health professionals agenda. Perhaps health professionals limit the amount of information they give to children in order to avoid distressing them, instead they attempt to promote optimism. Indeed, sometimes children did not mind being *"left in the dark"*, particularly if it meant they avoided hearing bad things. Alternatively, limiting the amount of information given to children might be an endeavour employed by health professionals' to minimise their own distress and ability to deal with children's reaction to information provided. Notwithstanding this, it neglects children's right to adequate and comprehensible information.

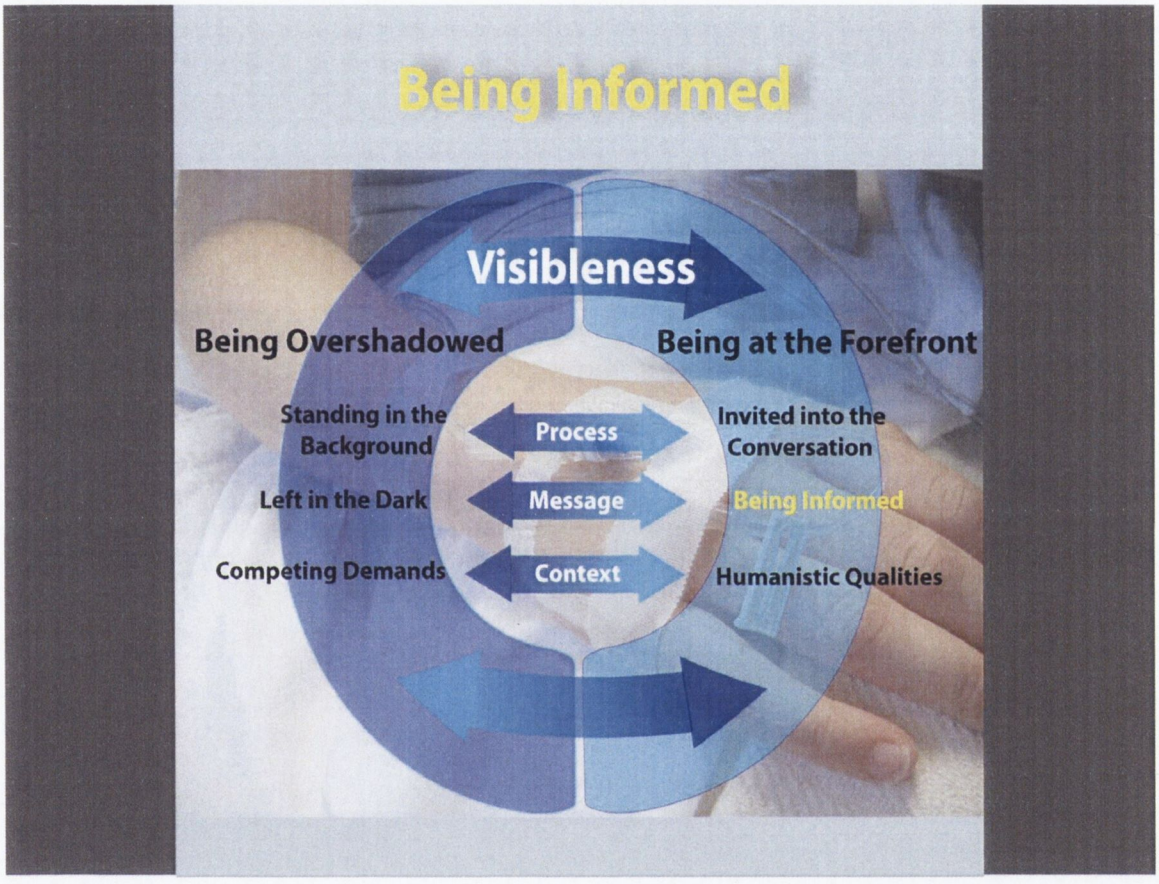
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[199] Smith and Callery (2005) explored the pre-operative information needs of children aged 7-11 years two weeks prior to their impending hospital admission. They found children possessed very limited knowledge and identified sixty-one questions about their impending hospital stay.

### 6.3.3. "Being informed"

Situated at the opposing end of the *"visible-ness"* construct, to the dimension *"left in the dark"*, is the second dimension of the conceptual extremity *"being at the forefront"*, which has been labelled *"being informed"*, illustrated below (Figure 12).

**Figure 12: Dimension *"Being informed"***




This dimension, *"being informed"*, constitutes the second aspect of the *message* of the communication process. In direct opposition to *"left in the dark"*, *"being informed"* refers to health professionals sharing information with children through explanation, orientation and education, in a format easily comprehensible to them. Children identified a range of health professionals who were pivotal in providing them with various types of information. Mostly, children expected and valued when the doctor as the 'knowledgeable expert' relayed adequate and comprehensible information directly to them. In such cases where the doctor neglected to inform children, the nurse held an

important 'intermediary' role, transmitting information to, and translating what the doctor had said, for children. Parents also often undertook this 'intermediary' role, transmitting and translating information for their child. Furthermore, some children actively navigated for comprehensible information themselves by questioning health professionals, their parents, interacting with other children and observing what was going on around them on the ward. The consequence for children of *"being informed"* was that it enhanced their knowledge, reassured, prepared and enabled them to make sense of what was happening around them. This helped to reduce their uncertainty and offered them some sense of control over what was happening.

Children identified a variety of health professionals (doctors, nurses, anesthetist, physiotherapists, and radiographers) who provided them with information, explained to them what was wrong with them and oriented them to what was happening. For example, while informally conversing with Katie and Maureen they talked about the physiotherapist providing them with information, as my field note extracts below illustrate.

> Katie talked about the physiotherapist. She relayed that the 'physio' listens to her chest and then tells her about her breathing, like "open up your lungs", Katie demonstrated by taking a deep breath and then said "get air in". Katie told me she felt that sometimes the physiotherapist tells her more than the doctors do. (Field Notes: Informal conversation: Katie 12 years: January 2005)

> Maureen told me about having to do her foot exercises every half hour. The physiotherapist had taught her how to do these. She demonstrated to me moving her foot and saying "this way and this" ... "that's to keep the blood moving" ... "because the cast is tight and it might stop it [blood]" (Field Notes: Informal Conversation: Maureen 12 years: February 2005)

However, mostly children talked about the doctors providing them with information about what was wrong with them and orienting them to what they were going to do. For example, Joanne talked about the doctor explaining to her what had happened when she was brought into the emergency department and informing her of changes he was making to the dosage of her medication.

> Joanne informed me that the doctor explained to her that she came in to the hospital by ambulance. She was in casualty for nearly two hours. The doctors had trouble getting the drip. Joanne showed me the bruises on her arms saying "look, they tried there and there"... "then they got one here and here" (pointing to the back of her

> wrist and her other arm). Joanne went on to say that the doctor told her he was putting up / increasing her medication to three times a day and then he'd see what her own doctor (name of consultant) would say. He'd leave it to her, to see what she wanted to do. (Field Notes: Informal Conversation: Joanne 14 years: January 2005)

Other children talked about doctors providing them with information about their impending surgery. For some children this included telling them about the operation risks, whereas for others it encompassed telling them about what might happen in the post-operative period. For example, Colm (13 years) stated that the doctors informed him specifically about the surgical procedure and risks, such as the possibility of damage to the optic nerve, blindness, loss of hearing and a change in his skin.[200] In the excerpt below, Maureen talked about her experience of receiving information on a number of occasions before her elective surgery.

> Maureen relayed to me that on [date] when she came to the outpatients there was a doctor there who explained the operation and procedure to her. He explained what he was going to do. He told her it was Hallux Valgus, which Maureen stated just means a bunion. Maureen also stated that she was told again on the day she came in to hospital again about the procedure and the operation, what they were going to do. She explained how the doctors showed her on her foot, marked it [foot] where they were going to cut. The doctors explained to her that they cut away something [she couldn't remember the name] and put something in the tendon to stop it pulling the foot outwards. (Field Notes: Informal Conversation: Maureen 12 years: February 2005)

This excerpt above illustrates the repetitious provision of information over time. This repetition and timing of information would differ for children undergoing emergency surgery. The first point of contact to receive information, for children admitted acutely, would be the emergency department. Gary relayed that the doctors in the emergency department told him he would probably need to get his appendix removed. Some time later, after Gary was fully admitted to the children's ward, he mentioned that the doctor returned, to review him again.

> When I entered the room, Gary told me that the doctor had just been. The doctor told Gary that he thought it could be his appendix or else a kidney infection or constipation and that he would be back later to see him before he decides about the

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[200] The views expressed by Colm contrast directly with those children in this study who preferred to be *"left in the dark"* and not hear distressing information, as referred to in Section 6.3.2.

> operation. Gary relayed that he had to have some tests done first…an ultrasound. (Field Notes: Informal Conversation: Gary 11 years: November 2004)

At a later stage, Gary talked about the doctor visiting him again, this time, to explain his impending operation to him.

> Gary told me that the doctor had come again. This time Gary stated the doctor had explained the operation, what they were going to do and all, how they were going to cut the smallest hole to get it [appendix] out. Gary informed me that the doctor told him he'd be stiff after the operation, he wouldn't be able to walk and he was now fasting. (Field Notes: Informal Conversation: Gary 11 years: November 2004)

Children also talked about nurses providing them with information about their impending operation and what to expect in the post-operative period. The following extract from an informal conversation with Maureen illustrates this point.

> Maureen informed me that the nurses told her about the anaesthetic and how she'd feel afterwards. The nurses told her that everyone might feel different after it [anaesthetic]….they said she might feel woozy afterwards with a sick stomach and told her if she felt like this that she was to just lie down and not get up. Maureen stated that they [nurses] also told her that her foot would be sore afterwards and that she might have pins and needles. Maureen relayed that she did actually have pins and needles afterwards…and her big toe was numb. They [nurses] also told her about medicines, the effects of the medicine like morphine. They had told her before the operation, like the effects. Maureen stressed that that was important because if you are sick after the operation and don't know why you might think something is wrong. (Field Notes: Informal conversation with Maureen 12 years: February 2005)

Like Maureen above, Stephen (11 years) reported that nurses provided him with information about what time he was going to have his operation at, that he would be asleep for about twenty minutes, about how he would feel afterwards and that he would be able to eat and drink after the operation. The nurses in casualty provided Gary (11 years) with information about the possible length of time he would have to stay in hospital for and how long he would be off school for if he needed to have surgery to remove his appendix. Rosie was able to describe and demonstrate accurately how to use her new inhaler. She was also able to distinguish, by colours, the different medicines she was required to take. The nurse had educated Rosie, as illustrated in the following extract.

> When I arrived into Rosie's ward, she informed me that she had to use an inhaler now. She went over to her locker and I followed. She showed her spacer[201] that she had to use until she got used to taking the inhaler on its own. She showed me how to use it, where to put the inhaler and demonstrated it by putting her mouth over the mouthpiece and breathing in and out....then she showed me the brown inhaler which she had to take once in the morning and once in evening, she also had a blue one she said which she could take if she needed it during the day. If she needed to take the blue one more than five times a week she could take two puffs of brown one morning and evening. When I asked Rosie how she knew all of this information she relayed that the nurse had told her. (Field Notes: Informal Conversation with: Rosie 11 years: February 2005)

While the above instances demonstrate children receiving information from both doctors and nurses, some children identified an information hierarchy existing at different tiers according to health professional status. Qualified doctors and nurses were seen as superior in their knowledge to training doctors and nurses, senior professionals superior to junior and doctors' superior to nurses. For example, Katie (12 years), a regular attendee to the children's ward, felt junior doctors, medical students, student nurses and even staff nurses would not be able to inform her about her illness or attend to her port-a-cath[202] because they lacked the required knowledge. Katie placed her consultant doctor and the clinical nurse specialist at the top of the information hierarchy, expecting information to come from them as 'knowledgeable experts'. Children who were regular attendee's to the children's ward were not exclusive in highlighting this concept of an information hierarchy of 'knowledgeable experts'. Joe (13 years) and Rory (12 years), both with no previous hospital experience, also expected to receive information directly from the doctor, believing the nurse might not have expert knowledge and consequently give incorrect information. This lends support to Buford's (2005), Beresford and Sloper's (2003) and Lewis et al's (2007) findings where children valued doctors' status and expected information to come directly from them.

However, in this study, when children did not receive information directly from the doctor they relied upon the nurse to act as an 'intermediary body' conveying to them

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[201] Spacers are used with inhalers for young children who might experience difficultly co-ordinating inspiration with medication release.

[202] Port-a-cath is an implantable venous access system, placed under the skin, usually in upper chest region. It is used for patients who frequently require intravenous access for antibiotics/fluids, etc.

what the doctor had said. The nurse was identified as pivotal, to interject and assist, in making it easier for children to understand the doctor. The following extracts from my conversational field notes serve to illustrate this point.

> Freddie informed me that his doctor had just been to see him. When I inquired what the doctor had to say, Freddie relayed "nothing he's a man of few words that guy"..."he doesn't say much"..."just prodding (pointing to jaw)". Yet, Freddie went on to tell me that he needed more bloods on Wednesday, that they [doctors] would stop 'them' [antibiotics] (pointing to the drip) tomorrow and then keep him in for another day to make sure his jaw didn't go up [swell] again. When Freddie had finished relaying all this information to me I asked, how did he know all this, since the doctor hadn't spoken much? Freddie stated that it was the nurse who had informed him. (Field Notes: Informal Conversation: Freddie 10 years: November 2004)

> Sue informed me that while the doctors often try to say things a bit easier sometimes she still can't make out what they are saying. Sue stated that the nurses can understand the doctor and then the nurses help her understand what the doctors were saying. Sue felt that "the nurses know we're not grown up" and they break down the big words the doctor uses. (Field Notes: Informal Conversation: Sue 12 years: February 2005)

In the first excerpt above, the doctor did not inform Freddie, but rather overshadowed him by his focus on the physical examination. Perhaps such an approach was not detrimental if some other person, in this case the nurse, informed the child. The second excerpt above demonstrates the nurse acting as an interpreter, translating the medical discourse for Sue. Through the doctor's use of difficult terms Sue was excluded and placed to the background of the communication process. Sue related her lack of understanding to her age and maturity and highlighted that the nurse recognised this and subsequently modified her language to Sue's level of understanding. In support of Sue, Kerry (13 years) felt nurses explained things simpler than doctors did. This mirrors Kilkelly and Donnelly's (2006) findings that in general children found it easier to understand nurses than doctors.

Children also relayed that parents acted as an 'intermediary body' between them and health professionals, transmitting information to and translating information for them. This lends support to Young et al's (2003), Buford's (2005) and Lewis et al's (2007) studies which reported that children relied on their parents' to act as "communication brokers" and "mediators" to reinforce and translate information provided by health

professionals. In this study, a number of children affirmed to me that not only did they prefer to receive information from their parents, but also they would be more likely to seek information and explanation from their parents if they did not understand what health professionals were saying. This was because they felt their parents were able to "make it simpler" for them. In the extract below, Stephen's mother provided some rationale for why parents can explain things simpler to their children.

> Stephen's mother relayed to me that the doctors told Stephen so much information that he would understand and then they told her more, more difficult 'stuff', that's harder to understand and then maybe she could explain it easier to Stephen. At this point I asked Stephen's mother why she thought parents could explain things easier to their children rather than staff. She stated that maybe it's because as parents they would be more used to explaining things to their own child and know what their own child would be able to understand. (Field Notes: Informal Conversation: Stephen's Mother: February 2005)

This provides some explanation for why health professionals might communicate directly with parents as opposed to children and why children do not particularly mind health professionals communicating with and informing their parents. The following scenario lends support to this argument. In this next extract, Rory highlights that his parents received "more important" information than he did. This was not a major concern for Rory because he believed his parents also needed to be informed. His parents would then act as an 'intermediary body' relaying the extra information to him.[203]

> Rory informed me that when the doctors told him what was wrong they did tell him directly but that his mam and dad were there as well. This was in casualty but also when he was on the ward if the doctors came to see him, when his parents were there or even when his parents were not there they would talk to him and tell him what was wrong. Rory went on to relay that the doctors did tell his parents more important things but not him but then his mam tells him, he stated. (Field Notes: Informal Conversation: Rory 12 years: February 2005)

In such instances, parents are an important information source for children assisting to bring them to the forefront of the communication process. Maybe, the important thing is that someone informs the child and assists in bringing him/her to the forefront of the communication process. In support of this statement, Stephen (11 years) and Ciara (13 years) informed me that it did not necessarily matter at what stage or who informed them,

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[203] Although this also allows the parent to filter the information he/she relays to the child.

as long as someone did, at some point. However, while parents are an important information source for their children, it does not negate health professionals from providing children with information, for children, like Rory above, valued information coming directly to them from health professionals. This equates with Buford's (2005) findings, that not only did children want information but they expected this information to come directly from health professionals. Parents in Buford's (2005) study also believed that it was important that health professionals communicate directly with their child. In cases where health professionals fail to provide information directly to children, children are then reliant on their parent(s) to inform them and ultimately move them to the forefront of the communication process. For example, as relayed by Rebecca in the extract below, although the doctor did not inform (nor communicate with) her directly, she received the information from her mother.

> Veronica: What were you told about the operation?
> Rebecca: They said they were going to put me asleep...well they told my mam.
> Veronica: Were you with your mam when they told her?
> Rebecca: No, she went out there (corridor)...they [doctors] called her out.
> Veronica: How did you feel about that?
> Rebecca: Well I think they should have told me as well.
> Veronica: So, how did you find out about the operation?
> Rebecca: My mam told me.
> (Field Notes: Informal Conversation: Rebecca 11 years: November 2004)

However, one difficulty inherent in parents acting as "intermediary information translators" is the degree to which parents understand the information themselves. As illustrated in the excerpts from my conversational field notes below, children believed that it was not only necessary for health professionals to simplify information for them, but also for their parents.

> Chloe informed me that the doctors had to "break it [information] down" not just for her, so that she could understand but also for her parents because "they [parents] hadn't a clue either". Chloe went on to say that then her parents talked about it [information regarding her operation] with her also and helped her to understand. (Field Notes: Informal conversation: Chloe 16 years: November 2004)

> Freddie relayed to me that at first the doctors used medical language then they used English language so that he could understand and also so that his parents could understand as well because as Freddie relayed "they [parents] don't understand it all either". (Field Notes: Informal conversation: Freddie 10 years: November 2004)

There were many exemplars of children describing instances of when health professionals exchanged complex terminology for easy understandable words and more developmentally appropriate explanations. This is an important component of the *message,* that it is delivered in an accessible format so that it is easily understood by the child recipient and his/her parent(s). This correlates with much anecdotal literature which suggests that effectively communicating with children requires finding an appropriate way that takes account of each child's development stage and maturity level (Jolly, 1981; Parish, 1986; Thompson, 1991; Chesterfield, 1992; May, 1999). While developmentally appropriate strategies were mostly instigated with younger children, aged 6-11 years, some older children, aged 12-16 years, also highlighted that simple explanations helped them understand better. This not only assisted children of all ages to understand what was happening around them, it also facilitated placing children at the forefront of the communication process, helping them feel included. For example, Rosie (11 years) told me that she was able to understand the doctor, because the doctor used easy words, such as "fizzy mask", to describe the nebuliser[204] to her. Similarly, Maureen (12 years) relayed how she was initially excluded when the doctors used medical language to converse with each other, however was later included when the doctors employed more understandable everyday terminology when conversing with her. The next two observational field note extracts serve to demonstrate the use of understandable everyday terminology by a nurse.

> Student Nurse: I'll just take your arm here
> Jodie: No response
> The student leaned in over the bed-table and placed the blood pressure cuff around Jodie's arm
> Student Nurse: just put this on your finger
> Jodie: No response
> Student Nurse: Are you in pain…sore?
> Jodie: No response
> Student Nurse: Now (name of girl) take your temperature
> Student Nurse: Now (name of girl) that's you finished and left
> (Field Notes: Observation: Jodie 9 years: November 2004)

Following the above observation I asked Jodie about "the thing" the nurse had put around her arm. Jodie informed me the nurse was "checking her muscles". This response

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[204] A nebuliser is a device for turning an aqueous solution of a drug into a mist of fine particles for inhalation (Cattell and Jones, 1995).

intrigued me and was later explained by another brief observation, as illustrated in the extract below.

> I observed an interaction between the student nurse and another little boy in the room who was just back from an operation on his foot. I heard the student nurse saying: "now can I check your muscles" (as she proceeded to take his blood pressure). The boy's mother repeated: "the nurse just wants to check your muscles". (Field Notes: Observation: November 2004)

Arguably, telling children that taking their blood pressure is "checking their muscles", reflects health professionals' innovative way of explaining different procedures to children to help them comprehend what is going on around them. Interestingly, a core paediatric textbook recommends:

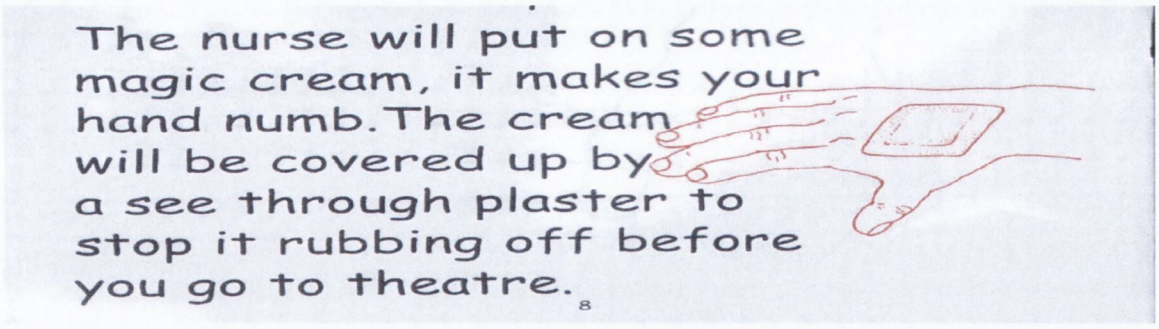
> "For children of preschool age and above, explain each step of the procedure and tell them how the cuff will feel such as a tight feeling or an arm hug. Use explanations such as "I want to see how strong your muscle is" or "let's watch the silver rise in the tube." (Hockenberry and Wong, 2005:144)

Joe highlighted that he was able to understand what was wrong with him because the doctors explained to him using tangible analogies, equating ligaments to elastic bands and muscle shrinkage to a pencil, as the following excerpt illustrates.

> Joe told me that the doctors informed him that it was like an "elastic band", that the ligaments move the knee case. He said the doctors just described it to him and showed him on his knee. Joe stated that the doctors told him his leg would be like a "pencil" when they take the cast off, the "muscles shrink" but this would be only for a day or two then they [muscles] get bigger again. (Field Notes: Informal Conversation: Joe 13 years: February 2005)

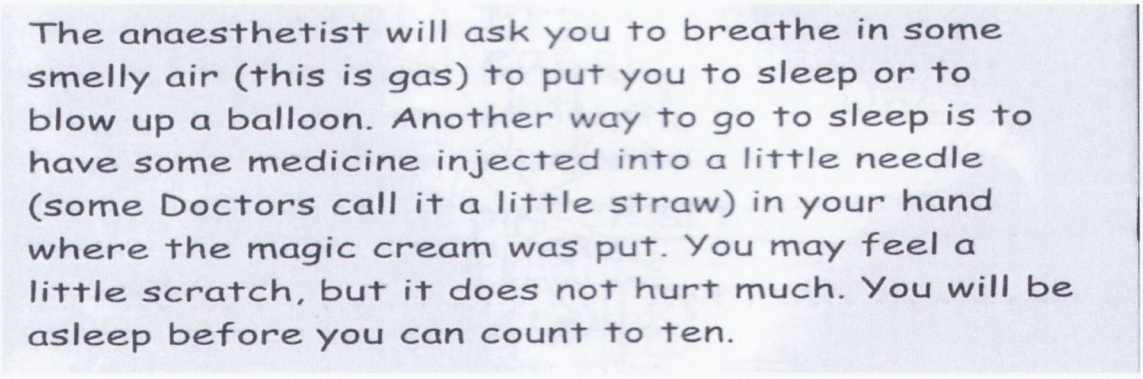
Another prevalent concept referred to by children was fantasy and magic. For example, before her operation Ann (8 years) mentioned getting the "magic cream" that numbed her arm. What was described by Ann equates to what was documented in the hospital preadmission book for children (see extract 2 illustrated below). Despite the availability of this booklet, it was not routinely given to children.

**Extract 2: From hospital preadmission book for children**




Some terms for anaesthesia used by health professionals were "sleepy water" (Ann 8 years) and "special medicine" (Damien 6 years). In addition to using magic, children mentioned concrete and real things that health professionals employed when communicating with them, such as "jelly on the belly" (abdominal ultrasound) (Mary 8 years, Rebecca 11 years, Gary 11years), "blowing up a balloon" (anaesthetic) (Mark 6 years) and "count to ten and you'll be asleep before you're finished [counting]" (Ann 8 years). Similar explanations and terminology reported by these children were used in the hospitals preadmission book for children, as shown in extract 3 below.

**Extract 3: From hospital preadmission book for children**



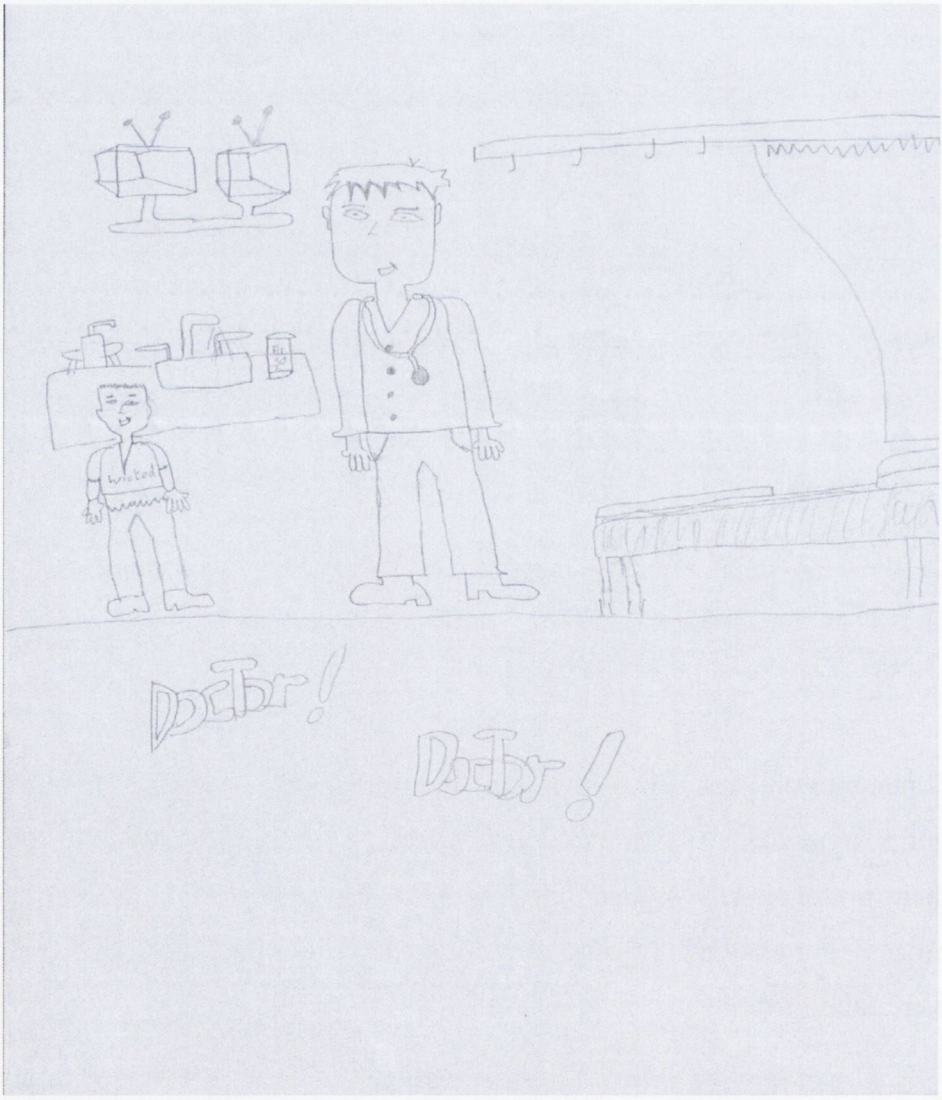

Sometimes children invented their own terminology to describe things for which they did not possess medical terminology. Arguably, by doing this, children attempted to make their presence known and bring themselves to the forefront of the communication process. For example, Freddie was able to describe what the nurses were doing when they were administering his intravenous medication. Yet, Freddie did not know the official

term for intravenous cannula so he invented his own idiom, drippy thing, as illustrated in this extract from my conversational field notes.

> Freddie described to me what the nurses did when they came to give him medication into his intravenous cannula. Freddie said that the nurses come and give water in a syringe. He said it is not a needle but something like it without the sharp bit. He stated he didn't know what you call it but that he calls it the "drippy thing". (Field Notes: Informal Conversation: Freddie 10 years: November 2004)

Similarly, when drawing a picture of when the doctor came to see him Sean drew the doctor with a stethoscope (as illustrated below). When asked about what this was, Sean replied that he did not know but that he refers to it as "the heart thingy". He went on to inform me that it was used to see if the heart beat was normal (pointing to left side of his chest).

**Drawing 6: Sean 10 years (November 2004)**

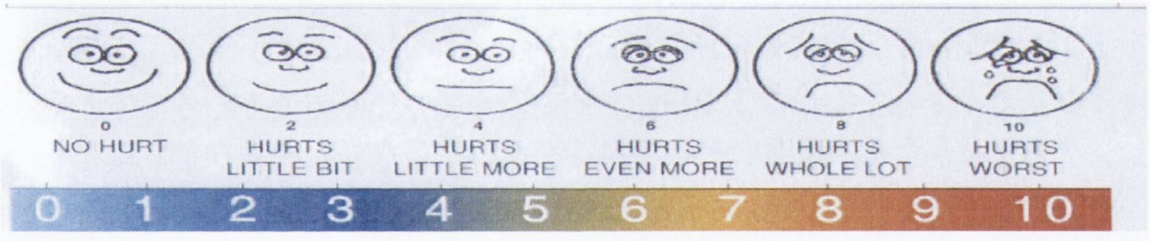


In the following interaction, Mark invented his own analogy to describe the oxygen saturation probe.

> Mark took the oxygen saturation probe off himself. As Mark did this he examined it intensely. I looked at it with him. Mark showed me the light asking if I could see it, he then went to put it on my finger. I held out my hand. As Mark did this I said ouch. Mark laughed saying …it's like a crocodile (opening and closing the finger probe). (Field Notes: Observation: Mark 6 years: November 2004)

Other communication strategies utilised by health professionals included employing additional tools, such as pain scales, to assist them in their interactions with children. For example, Freddie (10 years) described how health professionals explored his degree of pain with him through a "picture thing with faces", "like a happy one [face]" and "a sad one [face]", as illustrated below on the extract (number 4) from the hospital pain assessment documentation.[205]

**Extract 4: From hospital pain assessment documentation**




Gary recalled a similar experience describing a different pain scale; the numeric scale.[206]

> Gary informed me that the doctors and nurses ask him about his pain. To do this they [health professionals] used a scale of one to five. When asked the time by the nurse Gary stated his pain level was 4 and then the next time when asked by the doctor, who used a scale of one to ten, he stated five and a half. Then again on another occasion he said it was 8 and at this time he was given painkillers up his bum. (Field Notes: Informal Conversation: Gary 11 years: November 2004)

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[205] This is a well renowned pain assessment scale, entitled, Wong and Baker Faces Rating Scale, developed in 1988. It has been described as the most preferred pain assessment scale by children aged three to eighteen years (Carter, 1994; Twycross, Moriarty and Betts, 1998; Wong, Hockenberry and Wilson, 2007).

[206] Numeric scale is appropriate for children who can count and understand the value of numbers in relation to other numbers (Carter, 1994; Wong, Hockenberry and Wilson, 2007).

I also observed the use of the numeric pain scale in practice.

> The seconded student nurse was sitting beside Jodie's bed on a chair. The side rail of the bed was pulled up. Jodie was lying on top of her bed. The seconded student was asking Jodie about her pain. She said, are you sore? Jodie just nodded non-verbally that yes she was. The student nurse explored further asking Jodie was she a big bit or a little bit sore and used the scale one to nine to get Jodie to quantify the degree of her pain. (Field Notes: Observation: Jodie 9 years: November 2004)

Other tools that children mentioned health professionals employed to deliver information to and educate them were videos (Katie, to teach her about the port-a-cath), x-rays (Katie, to show her what was actually happening in the lungs), ultrasound (Sean, to show where his appendix was) and sponges (Kelly, to teach her injections). Kelly also mentioned she was given written information about diabetes and highlighted that there were different books, one for children and one for adults. Similarly, Orla (10 years) spoke about utilising a junior encyclopaedia of epilepsy and another book based on a detective story about a girl trying to find out about epilepsy, to seek information and understanding. Orla's mother had purchased these books for her. These aforementioned children (Katie, Kelly, Orla), except Sean, were children with long-term conditions.

A few children identified their age as an influential factor in determining whether health professionals informed them directly, in addition to, the extent to which they were able to understand any information relayed. For example, speaking from her experience of having undergone previous operations on her foot when she was much younger, Chloe felt that she given more information as she got older.

> Chloe informed me that when she was younger for her previous operations it was different, then the doctors would have told her mam and dad more, not her because she was too young. (Field Notes: Informal Conversation: Chloe 16 years: November 2004)

Katie expressed a similar view, believing the reason doctors might not directly inform younger children was because they would not understand, as illustrated in the extract below.

> Katie informed me that she believed for younger children the doctors tell the parents more because the child would not understand. She stated that younger children just miss their parents and if you just give them something to do they would be alright. (Field Notes: Informal Conversation: Katie 12 years: January 2005)

Although Maureen stated that she understood everything the doctor had told her, she felt that younger children probably would not understand. In the next field note extract, Maureen highlights the need to ensure that children of different ages are appropriately informed.

> Maureen informed me there was a young girl in the bed next to her and she heard the staff tell her about the "magic cream". Maureen went on to say that they didn't tell her "lies" or anything because there was no point. She stated that the staff knew that she was older so they told her that it would be sore and explained that she could get medicine for the soreness. (Field Notes: Informal Conversation: Maureen 12 years: February 2005)

Some of the older children linked their increased level of understanding directly to their schooling. For example, when Colm (13 years) talked about being informed of the risks of his surgery and how it might damage the "optic nerve", he stated that he knew this was the eye because he was doing biology in school. Similarly, Gary (11 years) stated he knew all the words the doctors used, such as "cranium", because he had previously learnt the words in school. Thus, tailoring the explanation to the child's age and level of understanding would assist in bringing the child to the forefront of the communication process.

Some children reported, or I observed them, actively navigating for comprehensible information. Children did this by questioning health professionals, their parents, interacting with other children and observing what was going on around them on the ward. For example, in the extract below from my conversational field notes, Freddie portrays that he was informed by the nurses, about what they were doing, because he asked them.

> Freddie informed me that the nurses informed him about what they were doing but probably only because he asked them about what they were doing. Freddie gave me an example of when the nurses come to connect him to the drip. Freddie described the bag that would be hanging (pointing to IV stand and pump) and stated that the nurses would squeeze the bag and then say 'about 10 minutes to go in'. Freddie stated he had asked then 'what's that for?' and the nurse had then informed him 'its water to flush it through'. (Field Notes: Informal Conversation: Freddie 10 years: November 2004)

In support of Freddie's view, in the following observation a student nurse did not orientate Sean to what she was going to do. Consequently, Sean asked the nurse

questions, seeking clarification about the task she was performing. As a result of not being informed by the nurse on the ward, Sean attempted to bring himself to the forefront and make his presence known by actively seeking clarification of what it was the nurse was doing.

> Student nurse to Sean: I'll just check these (walking to the side of Sean's bed with a mobile blood pressure monitor)
> Sean: Are you doing my temperature as well?
> Student nurse: Yes
> Student nurse: Now just put this here (placing blood pressure cuff around Sean's arm)
> Sean: Is this the one that gets tight?
> Student nurse: Yes .....but only for a few minutes
> As the student was waiting for the monitor to read Sean's blood pressure Sean's IV pump beeped. The student turned to reset the IV pump.
> Sean: It's gone down now (holding the blood pressure cuff on his arm).
> Student nurse: That's what its supposed to do (looking at the monitor). Look your arm is going all red...nearly purple even (looking towards Sean)
> Sean: It's cutting off me blood.
> Student nurse: OK, now, temperature (placing tympanic thermometer in ear).
> Student nurse: Now just put this (oxygen saturation probe) on your finger.
> Sean held out his finger and after the student nurse had placed the oxygen saturation probe on his finger he examined it holding it up to his face and looking at the light inside.
> Student nurse: Ok.....that's it, it wasn't too bad now was it.
> Student nurse left the room.
> After the student had left I asked Sean about what the nurse had just done. He informed me that he had them done in the emergency department as well and they were all explained to him down there but he couldn't remember what they were all for. (Field Notes: Observation: Sean 10 years: November 2004)[207]

The above observation was not uncommon. A similar scenario was observed when another student nurse approached Denzel to check his observations.

> While I sat beside Denzel 10 years a student nurse approached him. The student was checking the observations. Denzel was kneeling on the end of his bed facing the play station in front of him which was placed on a trolley at the end of the bed. I was sitting on an armchair next to Denzel's bed. Across the way was a girl whom Denzel was chatting to about the play station.

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[207] Through the questions Sean asked, he demonstrated that he did possess some knowledge of what the nurse was doing. This was because Sean had just been admitted to the ward and had previously had his observations checked in the emergency department. However, what is also illustrated here is that Sean wanted to be told about what the nurse was doing again, because although the observations were explained to Sean in the emergency department, Sean could not remember what everything was for. The need for the repetition of information and exploration of previous knowledge is emphasised here.

Student nurse: Just check your temperature....give us an ear (placing tympanic thermometer in Denzel's ear).
Denzel did not respond; he was not paying much attention to the student nurse. He kept playing away.
Student nurse: Can you put this on your finger?
Denzel held out his finger, although he was still transfixed on the play station. A second later Denzel asked.....What's that for?
Student nurse: To check your pulse .....your heart rate.
(Field Notes: Observation: Denzel 10 years: February 2005)

When children asked health professionals' questions, about what they were doing, it prompted the health professional to orientate and inform children. Similar issues emerged in Kilkelly and Donnelly's (2006) and Coyne et al's (2006) studies. In Coyne et al's (2006) study children highlighted the difficulty of obtaining information from doctors stating that the doctor would not explain unless the child asked. In Kilkelly and Donnelly's (2006) study health professionals themselves relayed that they would withhold information from children, unless children specifically requested information by asking questions.

It could be argued that older children would be more likely to ask questions. This would concur with Elliott and Watson's (1996) finding, where older children stated they would make themselves heard and ensure they were informed by persistently asking health professionals about what they were doing. In this study, younger children were also particularly inquisitive and asked questions about what was happening. For instance, in the observational extract below, Ann stimulated the staff nurse to provide an explanation by asking, *will it hurt?*

The staff nurse re-entered the room carrying a tray and approached Ann.
Staff nurse to Ann: Ok will we take that straw out of your hand?
The staff nurse sat on a small chair and the child sat on the floor. The child held up her hand up to the staff nurse.
Ann: Will it hurt?
Staff nurse: No the sticky plaster is the worst bit....first use spray....it's cold and now might pull a bit (as she tried to pull off the sticky tape).....Okay it's gone.....now a plaster for a few minutes.
Ann: Where did blood come from (pointing to dried blood on her hand)
Staff nurse: It's probably from when the doctor put it in ...maybe.
(Field Notes: Observation: Ann 8 years: January 2005)

Similarly, Collette, also interested in finding out about what the nurse was doing, prompted the nurse to orient her to what she is doing by asking, *what's that?,* as my observational field notes illustrate below.

> A staff nurse came in carrying a tray with spray, gauze and plaster.
> Collette was sitting on her bed, her mum sat in armchair beside Collette's bed. The nurse stood at side of the bed and placed the tray on the bed table in front of Collette.
> Staff Nurse: Now will we take out that in your hand, you don't want that going home.
> As the nurse proceeded to put on a pair of gloves Collette asked: What's that? (pointing to a bottle of spray on the nurses tray)
> Staff nurse: It's spray for the sticky plaster on your hand
> Collette: To wet it
> Staff Nurse: Yes I'll just get a tissue (walked to sink to get tissue)
> Collette: I can't wait to get this out
> The staff nurse walked back from the sink.
> The staff nurse began by spraying the sticky plaster and started to pull off the tapes, as she did this Collette started to whimper.
> The staff nurse stopped for a minute saying: You're ok…look I'm stuck to your plaster I'll have to come home with you.
> Collette: Smiled and laughed amid her tears.
> Collette's mother interjected: Oh wouldn't we love that.
> The staff nurse continued to pull off the tape and Collette whimpered more.
> Collette's mother held out her hand to hold Collette's hand saying: It's ok
> Staff Nurse: Now ok it's gone.... good girl.
> Collette showed her hand to her mother and her mother stated...more war wounds.
> The staff nurse put a plaster on Collette's hand and stated....look I'm stuck to you again (showing Collette how her gloves were sticking to the plaster).
> As the staff nurse was putting on the plaster Collette pointed to the IVC that the nurse had removed asking, what's that?
> The staff nurse showed the IVC to Collette saying ...it's like a straw (bending the IVC)
> Collette's mother: that's what they put in when you were in theatre yesterday.
> (Field Notes: Observation: Collette 6 years: February 2005)

Apart from Ann above, the majority of the younger children who asked questions had previous experience of attending the children's ward. Kilkelly and Donnelly (2006) contended that children who had considerable experience of healthcare settings tended to be more confident to ask questions.

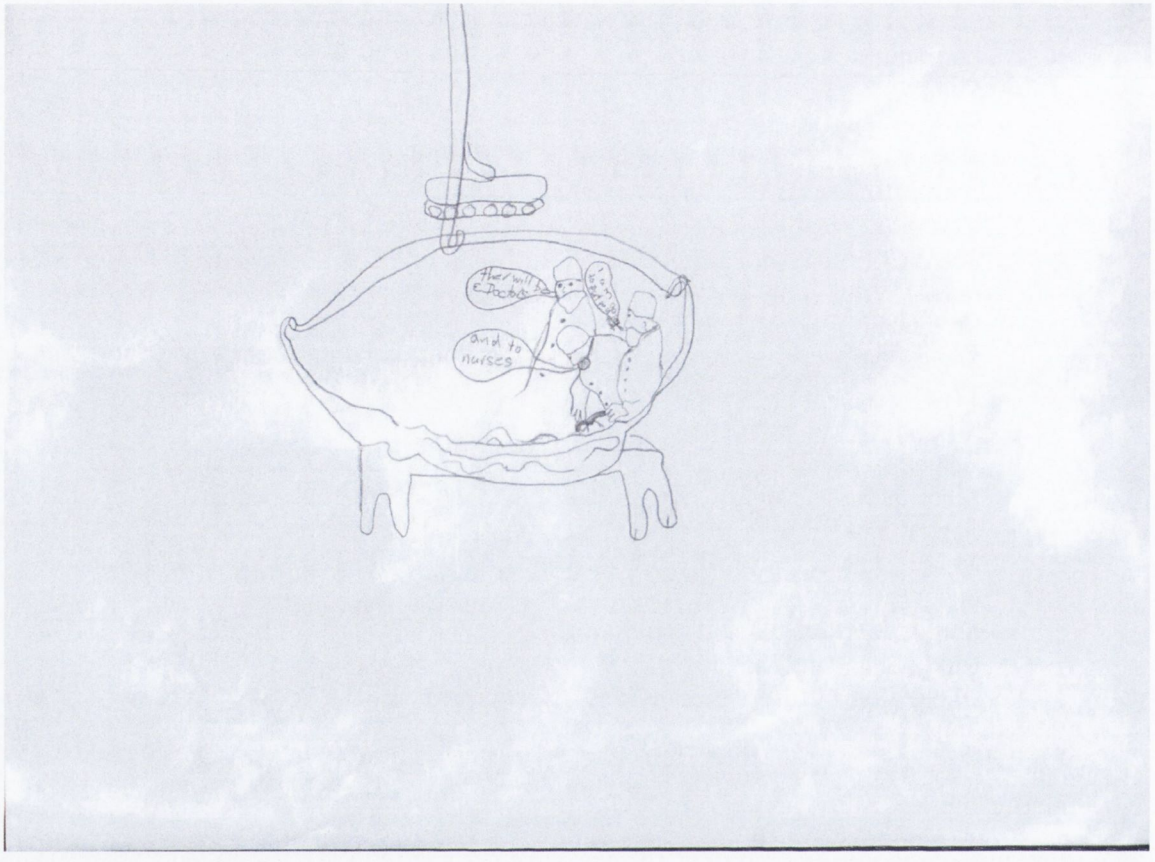
On a few occasions, I observed children interacting together and learning about what was going on around them through each other. For example, in the next observation extracted from my field notes, Mike relays information to Sonya.

I was sitting in an armchair next to Mike's bed, chatting informally to Mike. Sonya approached and stood at the end of Mike's bed.
Sonya: Is he fasting (nodding towards Mike 12 years)
I turned towards Mike.
Mike: No
Sonya: I have just come in 'cause I have a swollen jaw…don't really know why.....something to do with a filling or something.....that's sore (pointing to an IV cannula in her hand)….they put it in down stairs
Veronica: What's it for?
Sonya: For that (pointing to her jaw).....look its [pointing to intravenous cannula] red……..this is my second one
Mike: This is my thirteenth
Sonya: When my brother was in hospital before he got them loads of times ….like 17
Mike: I've had them all in one go
Sonya: It's sore
Mike: Is it sore when it goes in [when the nurse injects the medicine]
Sonya: Yes
Mike: Then it's probably done…out of the veins or something…you need a new one
Sonya: Is it sore when it comes out?
Mike: No...(smiled)....but then you have to get another one and that's sore.
(Field Notes: Observation: Mike 12 years and Sonya 10 years: November 2004)

Similarly, as Gary was drawing a picture about his experience of being in the operating theatre the previous day, Sean sought information from him. Illustrated below is Gary's drawing of people working in theatre. The people he drew wore hats, masks and blue clothes. Gary pointed to himself in his drawing lying on the operating table with one of the doctors holding a mask to his face. This was the gas. Gary drew a big set of lights above his head and some speech bubbles. In the doctor's speech bubble he wrote "I am going to put you asleep". Another doctor was saying "ther [there] will be 3 doctors and to [two] nurses". In the extract below, Gary and Sean interact.

Sean to Gary: Why do you have to wear a hat?
Gary: In case your hair falls into your appendix.
Sean: But your hair is there (pointing to his head) and your appendix is here (pointing to abdomen area)
Gary: (Shrugged his shoulders)
They then went onto talk about the gas that puts you asleep.
Gary: The mask is black and the gas smells….there were three doctors and two nurses….but I didn't see the nurses just the doctors
Sean: I want to go there [theatre] it sounds cool.
(Field Notes: Observation: Gary 11 years and Sean 10 years: November 2004)

**Drawing 7: Gary 11 years (November 2004)**




The above extracts illustrate that as children interact with each other they learn from each others experiences about what is going on and happening to them in hospital. Another source of information for children was observing what was going on around them in the children's ward. This is illustrated in the next two excerpts taken from my field notes.

> While I was chatting to Sean a trolley arrived. It was another child arriving back to the ward from the operating theatre (the sides were up on the trolley, which was covered with protective blue padding so you couldn't see into the trolley from where we were sitting). A porter dressed in green theatre scrubs and a staff nurse accompanied the child on the trolley. Sean asked me, what's that? I told him, it's a girl coming back from her operation. Sean stated I hope I'm not put on that. (Field Notes: Observation/Conversation: Sean 10 years: November 2004)

> As we were talking, a porter arrived to bring a child, in Maureen's room, to theatre. Maureen watched as the porter carried the girl, lifting her onto the theatre trolley. This prompted me to ask Maureen, can you remember how did you feel when you were going down to theatre? Maureen's response was, well just before I went I saw a child coming back [from theatre] crying, so that didn't help. (Field Notes: Observation/Conversation: Maureen 12 years: February 2005)

While observing what is going on around them on the children's ward might be a source of information/learning for children, the second extract above highlights that it may also be a source of anxiety when children observe distressing/upsetting situations.

In summary, *"being informed"*, is the second dimension of the conceptual extremity *"being at the forefront"*, which represents one aspect of the *"visible-ness"* construct. *"Being at the forefront"* also represents one aspect of the *message* exchanged within the communication process. In this dimension, *"being informed"*, a variety of health professionals placed children at the forefront of the communication process by sharing information with them through explanation, orientation and education. To include children, so that they are at the forefront of the communication process, information must be in a format and language appropriate to their developmental level. Health professionals used a variety of ways to accommodate to children of various ages, namely by using easily understandable words, developmentally appropriate explanations and alternative modes of communication. Although children described a variety of health professionals who relayed information to them, they valued information that came directly from doctors, viewing them as the 'knowledgeable experts'. Nurses and parents held an instrumental 'intermediary' role, transmitting to and translating information for children about what the doctor had said. Children themselves perceived their age to be an influential factor in whether they were directly informed by health professionals and the degree to which they were able to understand the information exchanged. Older children believed they were informed more, whereas for younger children information tended to be relayed to their parents more. Older children also felt that they understood more, partially as a consequence of their schooling. Children themselves also actively navigated for comprehensible information by questioning health professionals, their parents, interacting with other children and observing what was going on around them on the ward. The consequence for children of *"being informed"* was that it enhanced their knowledge and understanding, prepared them for the unknown and enabled them to make sense of what was happening around them.

### 6.3.4. Summary: *"Visible-ness"*: Message

To summarise, the information exchanged and its comprehension constitute the *message* of the communication process. The type, amount, format of the information and who exchanged the information determined the extent to which children were involved in the communication process and the extent to which children's agenda was addressed. This ultimately determined the extremity of the *"visible-ness"* construct which children assumed. This is whether children occupied the conceptual extremity *"being overshadowed"* or *"being at the forefront"*. The *message* linked the two opposing dimensions, *"left in the dark"* and *"being informed"*, each of which represented one aspect of the two conceptual extremities of the *"visible-ness"* construct, *"being overshadowed"* and *"being at the forefront"* respectively.

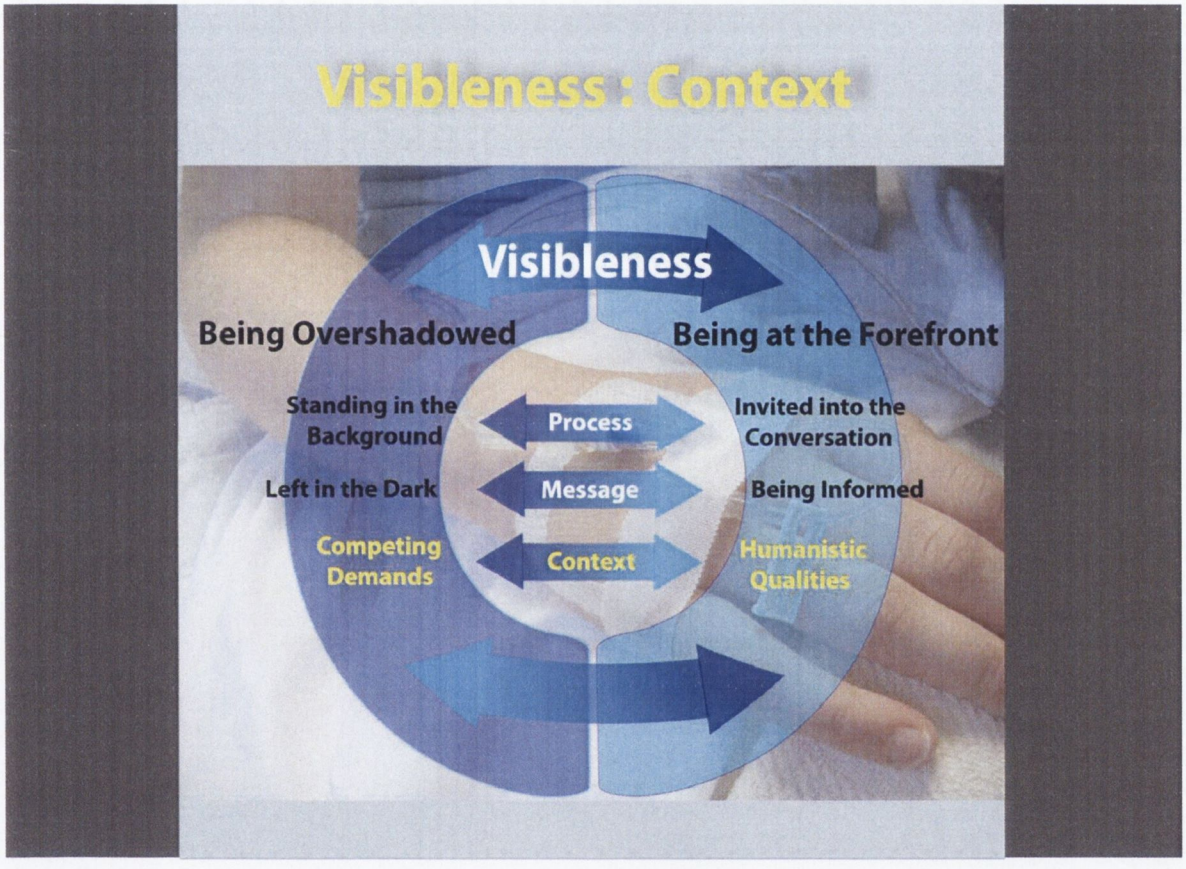
## 6.4. *"Visible-ness"*: Context

### 6.4.1. Introduction

In this section, the *context* in which the *message* was exchanged and in which the interaction *process* took place, between the health professional and child, will be outlined. The trans-circular model of communication recognises that communication does not occur in a vacuum, acknowledging that a variety of intrinsic and extrinsic factors can affect the interaction process and distort the transmission of the message. Broader extrinsic contextual factors, which might impact upon the nature of communication within the children's ward, will be referred to at a later stage within the discussion chapter (see chapter seven). The *context* referred to here relates to the immediate intrinsic environmental context of the children's ward, in addition to health professional qualities, which were central to creating the ambience of the internal ward context. These intrinsic environmental and humanistic factors were influential in either facilitating or hindering an effective process of communication. In general the intrinsic environmental factors consisted of elements which interfered with the interaction *process* and/or distorted the *message* being transmitted. Counterbalancing these inhibitive environmental factors were health professionals' qualities which were influential in creating an ambience which was more facilitative in nature. The *context* in which communication took place was

influential in determining the extremity of the *"visible-ness"* construct which the child would occupy, that is whether the child would occupy the conceptual extremity *"being overshadowed"* or the opposing conceptual extremity *"being at the forefront"*. The *context* was seen to comprise of the two opposing dimensions, *"competing demands"* and *"humanistic qualities"*, each of which represents one of the two conceptual extremities of the *"visible-ness"* construct, illustrated below (Figure 13).

**Figure 13: *"Visible-ness"*: Context**

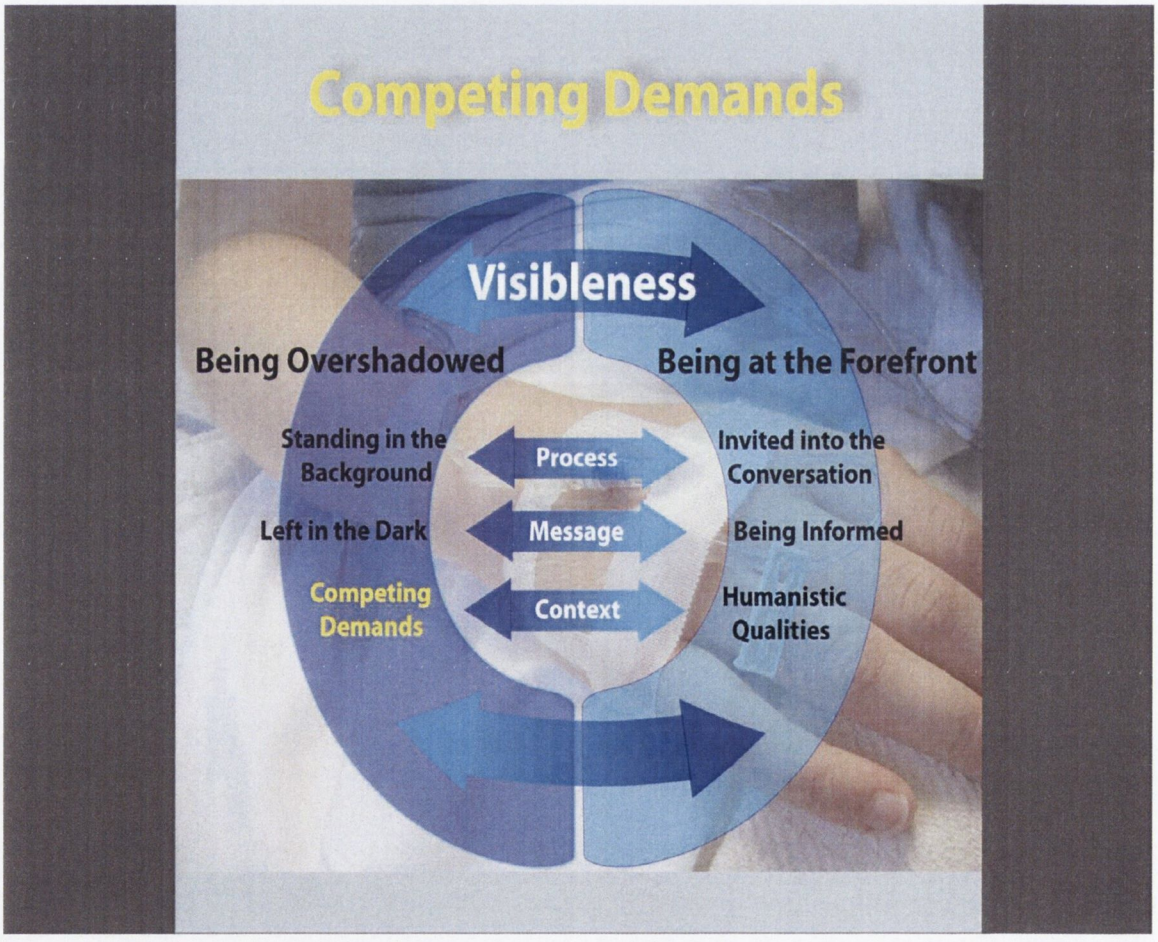



**6.4.2.** "Competing demands"

*"Competing demands"* is the third dimension of the conceptual extremity *"being overshadowed"*, which represents one aspect of the *"visible-ness"* construct, illustrated below (Figure 14 below). *"Competing demands"* also represents one aspect of the *context* in which communication took place between the child and health professional; that is the immediate intrinsic environmental context. Within this dimension, *"competing*

*demands"*, health professionals and children had to compete against internal ward environmental demands to communicate with each other. Children had to compete against "busy" "task oriented" health professionals, who were always in motion. This impeded children from making their presence known because they were reluctant to interrupt busy health professionals to ask questions. Also, at times children experienced difficulty accessing health professionals. Conversely, health professionals had to compete against incessantly "pre-occupied" children, who were constantly engrossed in play and education. Play and education were extremely important to children to assist with combating boredom, however arguably the "busyness" of children impinged upon the interaction process. Owing to these *"competing demands"* children were seen to be pushed to the background, overshadowed position, of the communication process.

**Figure 14: Dimension *"Competing demands"***

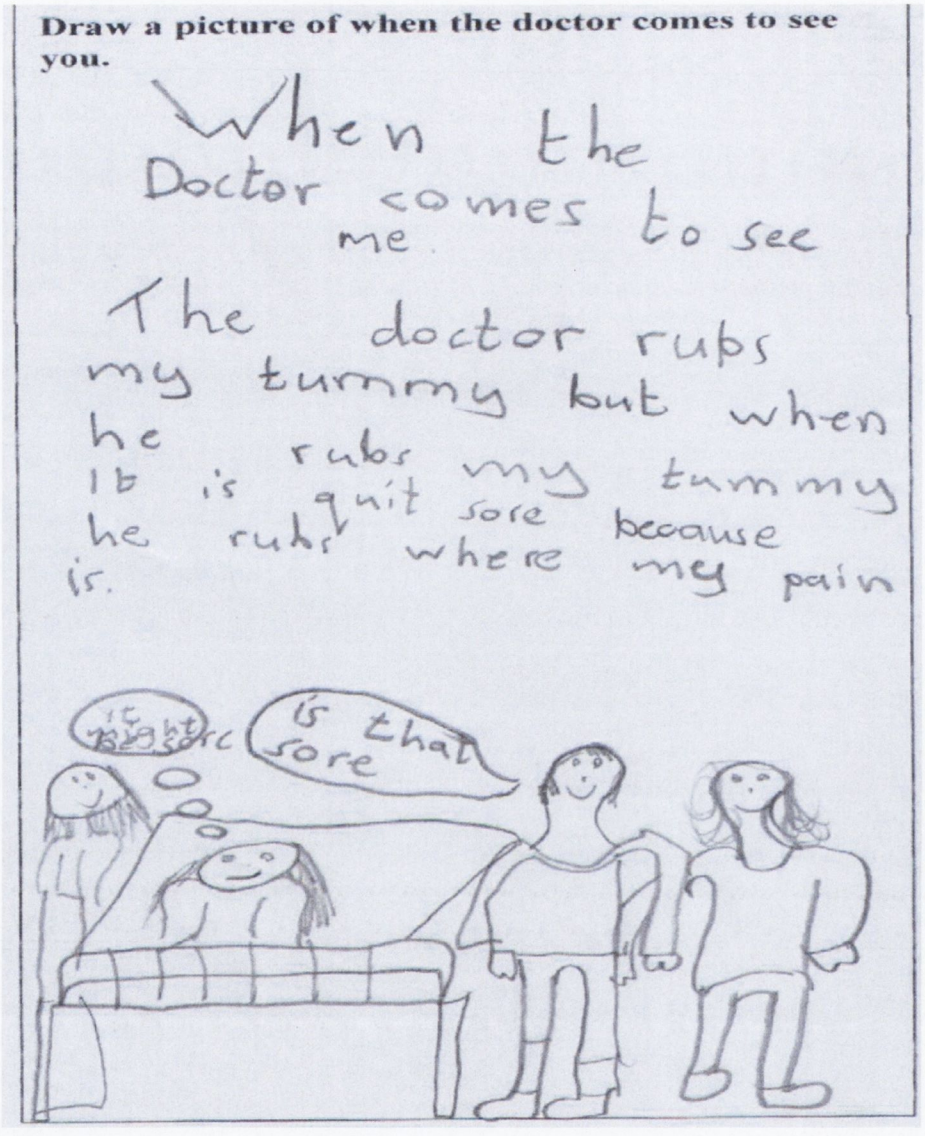


Health professionals' communication with children was predominantly organised around tasks (nurses) and examinations (doctors), focused mainly on physical symptoms, and highlighted by its absence, tended to neglect any emotional aspects of care. This focus on physical tasks and examination portrays an image of health professionals *"doing"* rather than *"being"* (by *being* I mean health professionals physically spending time with children outside the context of performing any examination/task/skill/intervention). Indeed, the primary reason for *"being"* with the child was to *"do"*.

For example, when conversing with children informally they frequently spoke about doctors examining them. For instance, Brian (10 years) informed me that when the doctors came to see him they would check "that" (pointing to the oxygen saturation monitor) and listen to his chest. Orla (10 years) expressed a similar view relaying that the doctor would listen to her chest and say "breathe in and out". Similarly, in her drawing, displayed below (drawing 8), Mary illustrates that the focus of the doctor's encounter with her was to examine her and assess her pain. Mary wrote that when the doctor came to see her he, "rubs my tummy but when he rubs my tummy it is quit sore because he rubs where my pain is". When examining Mary, the doctor asked "is that sore?" Mary relayed that she was nervous when the doctor came to see her because when he examined her, she was thinking "it might be sore".

Children also delineated that interactions with nurses centred round what they were doing. For example, Mary asserted nurses would come to her to check her temperature and blood pressure; ask her what she wanted for breakfast, dinner and tea and attend to her drip. This exemplifies the emphasis on physical tasks and activities of daily living. Similarly, Orla (10 years) relayed that when the nurses came to check her temperature, they put a "thing" [tympanic thermometer] in her ear that made a noise and then put a "thing" [oxygen saturations probe] on her finger. Brian (10 years) also spoke about nurses coming to routinely check his pulse and oxygen saturations every four hours.

**Drawing 8: Mary 8 years (January 2005)**




The focus on physical aspects of care was further evident within the *communication section* of the admission assessment documentation. Admission assessment documents were completed on admission for all children attending the children's ward where this study took place. These admission assessment documents were examined for two thirds of the child participants in this study. Data was extracted from a specific section of this form entitled *communication.* This revealed that the sole focus of the documentary evidence pertained to the assessment of children's physical ability to communicate. The most frequently recorded comments were *"hearing, speech and vision normal"* or any

difficulties with hearing and vision were highlighted. Table 6 below illustrates a sample of what was recorded verbatim on ten of the child participants' assessment in relation to their communication needs.

**Table 6: Assessment of Communication**

| **Communication Section of Admission Assessment Documentation** | **Sample of what was documented in the Communication Section of the Admission Assessment Documentation** |
|---|---|
| **COMMUNICATION (normal mode):**<br><br>**ALTERATION CAUSED BY ILLNESS:**<br><br>**REASSESSMENT (if required):**<br>**Date and sign entries** | 1. Speech, vision, hearing all normal according to mum.<br>2. Sight normal, Hearing normal, Speech normal. Alteration: nil anticipated<br>3. Hearing normal since grommet insertion, vision normal, speech normal according to mum.<br>4. Wears glasses reading/watching TV, no problems with hearing or speech<br>5. Hearing: decreased hearing Hx Grommets. Vision Nad/Speech Nad<br>6. Hearing, speech, vision all normal. Alteration cause by illness: hasn't been talking with as much ease as usual due to pain<br>7. Speech, hearing normal according to Mum. Eyes used to wear glasses. Squint operation Dec '04. Alteration nil anticipated<br>8. Hearing partially deaf in left ear, no hearing aid required. Speech & vision – mum says he has no problems.<br>9. (Child's name) wears hearing aid for reduced hearing in right ear, wears glasses, speech NAD<br>10. Hearing and vision good able to converse Alteration: nil |

These findings are supported by Irving et al's (2006) analysis of discursive practices used in nurses' assessment documentation, whereby nurses relied heavily on medical discourses with limited representation of psychological care. Irving et al (2006:155) stated that "the presence of predominately physical assessment silences the subjective narratives of the patient" and furthermore "what is not documented may be equally rational, such as more subjective descriptions of the problems from a patient perspective". Indeed, Broom (2007) postulated that assessment of the sick child in

hospital has become reductionist in nature merely viewed as a quantitative checklist. Broom (2007:23) challenged the necessity for more child and family focused assessments offering the following definition of what assessment should entail.

> "Assessment should be a dynamic, core clinical skill that opens discussion with the child and family, giving the nurse an opportunity to create a package of care based on best evidence, negotiated with child and family while meeting their unique needs".

This supports Faulkner's view that assessment is a dynamic ongoing process in line with the patient's ever-changing condition (Faulkner, 1998). Assessment employs interview technique and observation skills. The nurse must know the right questions to ask, be able to encourage patients to disclose information and be alert to and recognise clues that the patient sends (Faulkner, 1998). Perhaps, one inherent difficulty for nurses in assessing child/family communication needs is the way nursing documentation is organised, which can itself either hinder or enhance the documentary process (Casey, 2006). Another and perhaps more plausible explanation for the difficulties nurses face in assessing and documenting child/family communication needs is the lack of a structured framework to assist them in their practice. Broom (2007) contended that nurses can be supported in providing evidence based nursing interventions through a structural assessment process, which utilises theory to underpin practice. Alternatively, it is plausible that nurses in this study referred to the work of Smith (1995) for guidance in completing their admission assessment forms, because alongside drawing on Roper, Logan and Tierney's (1985) activities of daily living the children's hospital where this study took place also drew upon aspects of the Nottingham Model (see Appendix 41 for recommendations put forward by Smith (1995) for assessing children's communication needs).[208]

Lewis et al (2007) reported similar findings stating that interactions between nurses and children were opportunistic and incidental to the completion of tasks. Similar to child participants in this study, children (in Lewis et al's study) also spoke about interactions with nursing staff in the context of the tasks nurses performed. Indeed, also in Lewis et al's (2007) study, parents and nurses themselves spoke of nurses' *constant activity* and

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[208] There was evidence that the Nottingham model was incorporated into the philosophy of the children's ward as the use of the gingerbread man proposed by Smith (1995) was illustrated on the documentation.

*limited time* over which they had no control. Similarly in this study, within Barda Linbh, health professionals always appeared to be in motion, creating the concept of *"busy nurse syndrome"* as described by Martin (1998a). Martin (1998a) contended that continually attending to tasks keeps the nurse busy and this, justifiably, allows nurses to dissociate themselves from their patients, with no time available for nurse-patient interaction. This fact was also exposed by some of the children in this study. For example, Jodie (9 years) and Chloe (16 years) relayed that nurses would not sit or spend time with them, to chat or read a book because they were always busy. Colm (13 years) stressed that he did not blame the nurses for not having time to spend talking to him recognising their "busyness" and attributing this "busyness" to all the patients they had to look after. The nurses "busyness" is also captured in the following extract when Brian highlighted he waited a long time to get something he had requested, in addition to, nurses forgetting because of the numerous demands placed upon them.

> Brain relayed that he did ask the nurse for things, such as a drink of water. He went to say that one and a half hours later he got it. I asked Brain, why he thought this was? He stated that someone else probably called the nurse to do something and then she forgets and comes back later saying she forgot. He stated you have to remind them [nurses]. (Field Notes: Informal Conversation: Brain 10 years: November 2004)

Children expressed a similar view about the "busy" doctors. For example, Kerry, (13 years) highlighted that one reason the doctor may not have explained things to her was because he "always seems busy" and he "always has to go". Donal (12 years) informed me that the doctor told him that he "might get back later" to see him but that he was "busy all day". This implied, to Donal, that the doctor had a great deal to do, perhaps more important things than attending to Donal. The doctor had no time for further calls on his attention, with his "busyness" determining how often and when he would be able to come to see Donal. Health professionals' "busy" schedule meant that they had insufficient time available to interact with the children, thus preventing children from being brought to the forefront of the communication process. Consequently, children occupied the background position of the communication process, overshadowed by health professionals attending to their "task oriented busy" agenda.

This "busyness" and "task oriented-ness" of health professionals was an influential factor preventing children from actively intervening and moving themselves to the forefront of the communication process. For example, in the next extract, Katie's perception that the junior doctor was only interested in listening to her chest, and not to her, restricted Katie from asking a question about something she wanted to know. Thus, not only was Katie not placed at the forefront by the doctor, she also found it difficult to bring herself to the forefront as she was reluctant to interrupt the doctor's examination.

> While we chatted informally Katie informed me that the junior doctors don't really listen to her. She stated that she wanted to ask why she wasn't getting a nebuliser but she felt that the junior doctor just wanted to listen to her chest and but didn't listen to her. (Field Notes: Informal Conversation: Katie 12 years: January 2005)

Other children expressed similar sentiments, such as Annette (8 years) who stated that she did not ask questions, not because she was scared to ask, but because she did not get a chance to ask the "busy" health professional. The inaccessibility of health professionals prevented children from moving themselves to the forefront of the communication process. For example, John and Chloe identified that at night-time it was particularly difficult to get the nurses attention. In such circumstances, John and Chloe utilised parents of other children in their room to summon the nurse for them, as illustrated in the extracts below.

> John informed me that it was hard at night sometimes to get the nurses attention. This was because the door to the room was normally closed. When asked how John would get the attention of the nurse in such instances he relayed that he would ask the parents of the children in the beds next to him to get the nurses for him. (Field Notes: Informal Conversation: John 13 years: February 2005)

> Chloe relayed that the other night she wanted to go to toilet and called out for the nurse. However the nurse didn't hear her and a mother 'over there' (nearby bed) went to get the nurse for her. She stated she couldn't go herself because she had not received her crutches at that stage and she was also still on the drugs [morphine] so she was still a bit woozy. (Field Notes: Informal Conversation: Chloe 16 years: November 2004)

However, it was not always the case that health professionals "busyness" pushed children to background of the communication process. In the next isolated case, Sue emphasised that despite the fact the nurses were very "busy", and it was very late in the night, they gave up their time to listen to her. In this instance the "busy" nurses did not overshadow Sue, as illustrated below.

> Sue relayed that even though all the babies were crying the nurses sent someone to her as well. She stated that the nurses listened to her the previous night when she was in pain. She went on to say she felt listened to, that the nurses were trying to help, even though it was late and coming into the morning. (Field Notes: Informal Conversation: Sue 12 years: February 2005)

This suggests that "being busy" does not provide adequate justification for ineffective communication. It does not require more time but rather better use of communication skills during time spent with patients.[209]

The predominant focus on "doing" as opposed to "being" is in accord with previous and recent national and international literature, which reports that care of both 'adult' and 'child' patients continues to focus predominantly on physical tasks, such as checking vital signs, administering medications, attending to intravenous therapy, while psychosocial aspects of care receive less attention.[210] Nurses' "busyness" was found to account for lack of patient communication, legitimately enabling them to distance themselves from patients (Martin, 1998a; McCabe, 2004). This provided a protective mechanism against any emotional aspects of their work and avoided dealing with the fear of any negative consequences of such interactions and/or the fear of losing control (Faulkner, 1998; Wilkinson, 1991; Perry and Burgess, 2002, Freshwater, 2003). Jenner (1998) reported that while a "task oriented" approach may not be in patients' best interests it may be a crucial strategy to assist nurses to cope with increasing stress levels. Morse et al (1992:817) supported this view as the following quotation demonstrates.

> "The mechanism of detachment is probably a necessary process that enables nurses to overcome the stress caused by the patient's suffering that is associated with certain procedures and treatments".

Morse et al (1992) contended that in order to avoid emotional exhaustion nurses control their experiences of patient suffering by limiting their involvement with patients; achieved by using "busy nurse persona" (McCabe and Timmins, 2006:15). However, such distancing seriously prevents the disclosure of patients' concerns. McCabe and

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[209] In Wilkinson's (1991) study, which compared six wards, the best communication took place on a busy ward.

[210] For example, see Schulman, Kasper and Child (1970), Cleary (1979), Crotty (1985), Holyoake (1998), Rosalind and Wright (1999), Henderson (2003), McCabe (2004), Shin and White-Traut (2005)

Timmins (2006) highlighted that although fundamental task accomplishment may take the priority of care, in this era of cost and quality driven agenda's, extending the nurses role beyond such a task focus would serve to address patients' needs in a more meaningful way.

As mentioned previously, *"competing demands"* does not only refer to "busy" health professionals but also to "busy pre-occupied" children. The corollary of the "busyness" of hospitalised children has not been previously documented. In this study, despite their 'sick role', children were incessantly "busy"; "pre-occupied" with school, play and activities. This lends support to Curtis, James and Birch's (2007) contention that children as a category are denied full access to a 'sick role' in hospital. Similar to health professionals, children in this study were continuously in motion and often spent a lot of time off the ward in the hospital playroom or primary school, as described in chapter 5. When children, of all ages, talked about what they liked most about hospital, and what they did all day in hospital, they principally referred to visiting the hospital playroom and school. The children who for whatever reason could not leave the ward area (e.g. bed-bound, acutely ill) to attend the hospital playroom or school engaged in more sedentary play[211] activities on the ward, such as, watching television, watching films on portable DVD players, playing the game-boy, play-station or X-box (console game systems) or taking part in school activities. The next extract illustrates some of the things Joe relayed that kept him busy on the children's ward.

> Joe spoke about what he did all day in hospital, relaying that he watched television, videos, played the play-station and game-boy. He mentioned that the television is turned off at 10pm; then he would read his books. His parents also come to visit and bring McDonalds. Joe had never been in hospital before and went on to say that it was better than he thought. He thought it would be horrible and said that he didn't realise that there was the play-station, which could be brought to him and also the school teacher who comes to the ward as well. (Field Notes: Informal Conversation: Joe 13 years: February 2003)

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[211] In this study I use the words 'play' and 'activity' interchangeably and in a broad sense to incorporate a myriad of activities (such as playing games, watching TV, playing game-boy) and all age groups of children.

Being "busy" was extremely important to children. Denzel (10 years) told me the reason he was so engrossed in and loved the play-station was because it kept him busy and he reiterated that he liked to be kept busy. "Being busy" helped to combat children's boredom. On occasions when the playroom and school were closed, such as at weekends and in the evening times, children talked about being bored and fed up. This equates with findings from other studies which confirmed that according to cultural norms children needed to keep occupied to avoid boredom (Curtis, James and Birch, 2007; Coyne and Conlon, 2007). This was not a surprise finding, for play (activity) and childhood go hand-in-hand; play been described as a universal activity and defining feature of childhood (Greig, 2005). Lansdown (1996:63) referred to play as "the food and drink of mental growth" and thus "an essential requirement for a child's well-being and development". Therefore, it is not surprising that play/activities are recommended as an integral part of a child's hospital stay, being not only beneficial in entertaining children, but also a powerful form of distraction; creating an environment which minimises stress and anxiety and makes the unfamiliar somewhat familiar, thereby facilitating adaptation and adjustment.[212] Walker (2006) contended that the availability of play equipment itself signals to the child that children are welcome here.

However, despite the extreme benefits of school, play and activities for hospitalised children, the impact of these activities on the communication process, which takes place between children and health professionals in a hospital setting, has not been previously documented. A key question to ask is; what is the impact of children's busyness on social interactions and relationships with health professionals? For instance, it has been reported that the time children spent watching television, with or without their parents and siblings present, negatively influenced the time that was spent interacting with parents and siblings (Vandewater, Bickham and Lee, 2006). Other studies have also shown that engagement in computer games affects children's sociability, impacting upon friendship and family interactions (Subrahmanyam et al, 2000). Thus, is it plausible that the time

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[212] (Doverty, 1992; Levieux-Anglin and Sawyer, 1993; Association for Welfare of Children in Hospital, 1993; Corlett and Whitson, 1999; Webster, 2000; Children in Hospital Ireland, 2002; Haiat, Bar-Mor and Shochat, 2003; Scarlett et al, 2005; Donnelly and Robinson, 2006; Walker, 2006).

hospitalised children spend engaged in school, play and activities negatively impacts upon the amount of time health professionals spend interacting with children? Furthermore, these activities create an abundance of commotion, distractions and noise, which ultimately impacts upon the effectiveness of the communication process. Arguably, health professionals have to compete for children's attention in order to communicate effectively with them. The following extract of an observed interaction between Holly, her mother and a doctor serves to illustrate this point.

> A female doctor arrives to review Holly. Holly is sitting on her bed with a bed-table in front of her drawing. Her mother is sitting on one side of the bed and I am sitting on the opposite side. The doctor walked into the room towards the bed and stood next to Holly's mother who remained seated.
> Doctor to mum: I'm (name), the SHO. How is she?
> Mum: She's better
> Doctor to Holly: How are you?
> Holly: (Smiled, no verbal response)
> Doctor to Holly: You're too busy, very busy
> Mum to doctor: Why is she in here? What is wrong with her?
> The doctor provided mum with an explanation stating that because her daughter had asthma when she's gets a cold it tends to go to her chest.
> Mum to doctor: What did the x-ray show?
> Doctor: It was okay…viral.
> The doctor went onto explain to mum the child's treatment, nebulisers and steroids. Also as the child needed oxygen during the night she they had to keep her in hospital again tonight to see how she got on.
> Doctor to Holly: Can I listen to your chest? Can you open your (PJ) top?
> Holly opened her PJ top
> Doctor to Holly: Take a deep breath
> Doctor to mum: She's still wheezy. I'll add in another nebuliser. I won't be here tomorrow but see how see is overnight and she might be able to go home tomorrow. As it's the weekend I'll leave instructions with the nurses. Okay, see you later.
> Holly didn't say anything but she was looking up at her mother and the doctor as they spoke, especially when going home was mentioned, Holly's ears cocked up and she looked up in the direction of the doctor smiling.
> (Field Notes: Observation: Holly 6 years: December 2004)

In the above excerpt following an initial introduction and question directed to Holly's mother, the doctor did direct a turn in the conversation to Holly, asking her how she was. However, Holly did not verbally respond, she just smiled. The doctor related Holly's non-response to the fact that she was "busy". Consequently, the conversation was redirected to Holly's mother. A similar scenario was observed when a clinical nurse

manager came to see Mark. Mark was engrossed in his drawing and did not respond to the clinical nurse manager, as the observational extract below illustrates.

> A CNM arrived to say hello to Mark. Mark was sitting on the edge of hid bed with a bed table in front of him, he was drawing. The CNM got down on her hunkers at the other side of the table and looked across at Mark.
> CNM to Mark: Hello Mark how are you back to us again
> Mark continued to draw. He didn't look up or didn't say anything.
> Mark's mother: Are you not going to say hello to (name of CNM)
> Mark: Hello
> CNM: How are things? Are you ready for Santa? Have you written your list yet?
> Mark: No not yet
> CNM chatted to Mark's mother for a few minutes
> CNM to Mark: I'll come back when you're not so busy and have time to talk to me
> Mark: Ya (Field Notes: Observation: Mark 6 years: November 2004)

Through children's non-responsiveness and pre-occupation with what they were doing, health professionals may perceive that children do not want to be included or communicated with. Health professionals might be reluctant to disturb "busy" children, presuming, because of their "busyness", they are happy and content. The difficulty inherent here is if it is surmised that "busy", "pre-occupied" and easily distracted children do not have any worries or concerns. This is not too dissimilar from the quiet child who is often assumed to be pain free, as opposed to the child who is more vocal and thus more likely to be perceived as being in pain (Brown and Timmins, 2005; Twycross and Unsworth (neePeden), 2007). Maybe children's limited responses were because they were not expecting to be included in the conversation and thus they were wary of health professionals who did communicate directly with them. Regardless, children's active participation in the communication process is blocked, placing them to the background, overshadowed position, of the communication process.

In this study, attention was drawn to the fact that play, as a therapeutic tool,[213] was not fully capitalised upon. Rather, play was used occupationally, to keep children occupied.

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[213] Play as a therapeutic tool refers to the purposeful use of play activities (any kind) to facilitate communication with children (DelPo and Frick, 1988). It is a means to assist children to express their thoughts, feelings, fears and help them master and cope effectively. It differs from play therapy (used in psychotherapy) which aims to diagnosis emotionally disturbed children (Chambers, 1993; Scarlett et al, 2005) and contrasts with normative play, whereby children engage in spontaneous play (Donnelly and Robinson, 2006).

Being occupied is having something to do that takes up a great deal of time and requires attention. It is a welcome means of filling time with less time to think about being sick. While not to devalue the diversionary aspect of play (Chambers, 1993), arguably, by employing play as a language and not merely as an activity the health professional would be equipped with a valuable communication tool (Donnelly and Robinson, 2006).

The last few years have witnessed a monumental change in play activities with a substantial increase in technologies such as game consoles, which are now widely available and, as evident from my ethnographic field notes, have become an integral part of the children's hospital. Scarlett et al (2005:115) contended that "because of electronic play, we are in the midst of a play revolution". Perhaps alternative modes of communication are required, that keep abreast with modern technologies, to enable health professionals to effectively engage with and capture children's interest. Technology is fast becoming integrated into all aspects of our lives and has resulted in huge changes in the way we communicate, for example, text messaging, e-mailing, and chat rooms. Children are growing up in a technological era and fast becoming masters of these various technologies, which are now natural mediums through which children communicate. Does communicating through such technologies require the use of different types of communication skills and different types of language? What impact does this technological change in communication patterns have on children's social development? Do technologies hinder development of interaction/interpersonal skills or do children develop different types of interpersonal skills? What impact would the use of technologies, such as the play-station or game-boy, as a medium of communicating with children have? How would it effect face-to-face interpersonal communication? Would it serve to dehumanise communication by displacing social human contact and interactivity? Would the responsiveness and engagement of human interaction be lost?[214]

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[214] Scarlett et al (2005:115) provided some explanation for why a number of questions are raised here; "because we are in the midst of and not beyond this [electronic play] revolution, there are more questions than there are research based answers – questions about how electronic play affects children in the long term, whether the electronic play promotes violence, the importance of the differences between electronic play of girls and boys, and how the effects of electronic play will influence families and parent-child relations".

Conversely, such interventions could assist in increasing children's locus of control, capture different learning styles and may also be of benefit to parents, siblings and peers as suggested by Dragone et al (2002), who reported on a CD ROM developed to provide access to knowledge for children with leukaemia. Dragone et al (2002) recommended the CD Rom as an ideal medium for translating information into a format more easily understood by children. The need for more specific information resources for children, including some which could be accessed through technology such as the World Wide Web, was recently highlighted by Walters and Coad (2006) for children undergoing spinal surgery.[215]

In summary, this third dimension, *"competing demands"*, of the conceptual extremity *"being overshadowed"*, represents one aspect of the *"visible-ness"* construct and one aspect of the *context* in which communication took place between the child and health professional; that is the immediate intrinsic environmental context of the children's ward. This dimension, *"competing demands"* refers to the "busyness" of both health professionals' and children. Health professionals were "busy" attending to tasks and examinations; with nurses' seen to organise their work and communication with children around physical tasks and doctors around examinations. Health professionals' busy schedule meant that they had insufficient time available to interact with children. This prevented children from being brought to the forefront of the communication process. Additionally, this prohibited children from bringing themselves to the fore. Health professionals also had to compete against "busy" children in order to communicate effectively with them. Thus, children's inclusion in the communication process may be blocked by their own "busyness", being constantly engaged in play and school activities, either on or off the ward. Finally, attention was drawn to the fact that play activities were predominantly utilised as diversionary and occupational tools as opposed to therapeutic. It was argued that perhaps alternative modes of communication are required, that keep abreast with modern technologies, to enable health professionals to effectively engage with and capture children's interest.

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[215] Refer also to Clough (2005), Robinson, Hughes and Manning (2002) and Terry and Campbell (2001) for further examples of calls for the need for more innovative information resources.

### 6.4.3. "Humanistic qualities"

The third dimension of the conceptual extremity *"being at the forefront"* has been labelled *"humanistic qualities"*, illustrated below (Figure 15). This dimension, *"humanistic qualities"*, also represents the second aspect of the *context* in which communication took place between the child and health professional; that is health professionals' personal factors which were influential in shaping a ward ambience which was more facilitative in nature. The *"humanistic qualities"* of health professionals counterbalanced and assisted health professionals to cope with the *"competing demands"*, described previously (Section 6.4.2). *"Humanistic qualities"* incorporates such elements as nice, friendly, humorous and approachable health professionals who despite "being busy" demonstrated their presence to, and acknowledged the presence of, the child. Owing to the *"humanistic qualities"* of health professionals children were temporarily placed at/moved to the forefront of the communication process.

**Figure 15: Dimension *"Humanistic qualities"***



The majority of children mentioned positive humanistic attributes displayed by health professionals. For example, Sinead (9 years) referred to the nurses as "nice", "kind", "friendly" and "helpful". Similarly, Jodie (9 years) described the nurses as being "certainly not horrible". Health professionals' nice and friendly characters were also evident non-verbally in their facial expressions as highlighted by Jodie when she remembered a doctor from the operating theatre because "he just smiled". Smiling indicates receptivity, friendliness and conveys a warm message. Warmth and friendliness was also displayed through the use of humour. Some children reminisced about health professionals joking, messing, teasing and being funny, as illustrated in the excerpts below from my conversational field notes.

> Orla relayed that the nurses teased her about her medicine whether she had it or not. She stated that the staff nurses say "are you sure you have taken it [medicine], I don't think you have", then they would say "you're right you have" (Field Notes: Informal Conversation: Orla 10 years: January 2005)

> Joanne told me that the doctors were funny and joke around, she mentioned her consultant doctor stating that he was funny and joked around and was always in good humour.(Field Notes: Informal Conversation: Joanne 14 years: January 2005)

> Katie described a scenario that happened this morning. The male (post registration) student nurse who was caring for Katie today was trying to get her up out of bed. She said she saw the student nurse coming with water and she hit out at him. This sent the water flying and she relayed that the student nurse wasn't able to talk he was laughing so much. She stated "he's so funny. (Field Notes: Informal Conversation: Katie 12 years: January 2005)

Humour is said to have beneficial effects on nurse patient interactions and on the nursing climate (Mallett and A'Hern, 1996; Astedt-Kurki and Isola, 2001). It creates an unconstrained positive ward atmosphere. Hargie, Saunders and Dickson (1994:256) proposed humour enhances "the audience liking for the presenter" and assists in the development of a trustworthy relationship. Humour can also be effective in relieving tension and dealing with stress and anxiety, helping both health professional and patient to cope with difficult situations (Astedt-Kurki and Isola, 2001; Dowling, 2002). The following excerpt, from my conversational field notes, serves to illustrate this point, in

which Damien highlighted the influence of the porter in helping to reduce his anxiety *en-route* to theatre, by being funny.

> Damien: He's [other patient Lee 6 years] a long time.
> Veronica: Where's he gone?
> Damien: To where I was yesterday
> Veronica: Where was that?
> Damien: In the lift …down big long corridor
> Silence as Damien drew
> Damien: But I wasn't scared because the man was so funny
> Veronica: The man [porter] was funny …what did he say?
> Damien: He was talking about pirates and he was so funny
> (Field Notes: Informal Conversation: Damien 6 years: November 2004)

The use of humour in an attempt to dispel anxiety is further illustrated in the following extract, taken from my observational field notes.

> Later I observed as the trolley (theatre) arrived to take Collette to theatre. Standing around the trolley as Collette got up on it were the porter, Collette's mother and father, clinical educator and a clinical nurse manager. Collette looked as if she was initially laughing then suddenly she burst into tears. The clinical nurse manager stated "ah Collette, we can't have that, don't worry". The porter interjected stating "I thought you were laughing, what's this crying?" The clinical nurse manager stated "were you drinking Guinness at lunchtime", "think of your brother coming in to see you later". Then the clinical nurse manager started to run and the porter started to push the trolley, she stated "I better run or I'll be knocked down by (porters name)". Collette displayed a mixture of tears and laughter. (Field Notes: Observation: Collette 6 years: February 2005)

While this excerpt illustrates the use of humour as a means of dispelling anxieties, it also illustrates the superficial nature of humour and the neglect of acknowledging and exploring Collette's true concerns. Dowling (2002) contended that humour is adoptive when it helps the child through a stressful situation. However, Dowling cautioned against the persistent use of humour, which avoids acknowledging the existence and verbalisation of feelings. Then humour becomes a maladaptive process. In both Collette's and Damien's situations, illustrated above, perhaps the use of humour was appropriate at this time in an attempt to help distract them from their fears *en-route* to the operating theatre. Timing, receptiveness and context must be considered when determining the appropriateness of using humour (Dowling, 2002).

The use of humour is not only about reducing fears and anxieties but also about establishing a warm interpersonal relationship and creating a warm, friendly and relaxed

atmosphere on the ward (Sheldon, 1996). Having fun was particularly valued by and central to the children's agenda in this study. Children particularly referred to student nurses having a laugh, being fun and playing with them. Katie (12 years) relayed that student nurses often talked to her more than staff nurses; and this was at a different, more social humorous, level.[216] Brian also valued the time students spent having a laugh and fun through play, as illustrated in the following extract.

> Brian informed me that the "training nurses are better". He clarified that I knew who the training nurses were identifying them by the two crests that were displayed on their uniforms (he put his hand to his chest illustrating the position of the crests on the uniforms). Brian went on to say that the reason why the training nurses were better was because they played, they took time out and had a laugh and some fun. (Field Notes: Informal Conversation: Brian 10 years: November 2004)

Some student nurses, especially those at undergraduate level, were observed playing with and entertaining children. For example, they played cards, board games and did jigsaws. The fact that undergraduate student nurses held a supernumerary status and were not allocated a patient case-load or certain tasks to complete could explain why these students were able to take time out of the "busy" ward schedule. In such instances, these student nurses helped to counterbalance the *"competing demands"* of the qualified staff by spending time and playing with the children. The humane qualities, as described by the children, are consistent with those reported in a Finish study, which examined what children, as patients, considered important in quality nursing care (Pelander and Leino-Kilpi, 2004). Similar to this study, children expected nurses to be nice, friendly, pleasant, cheerful and humorous.

*Being nice* is often a concept not well defined. For children in Pelander and Leino-Kilpi's (2004) study being nice meant that nurses were helpful, kind and played with children. In this study, some children were unable to articulate exactly what it was that was nice about the health professionals, whereas other children were able to expand upon what "being

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[216] This links with what was described previously under the dimension "being informed" (section 6.3.3), where children did not view students as having an information giving role. Alternatively here under this dimension, "humanistic qualities", children valued students' social role. Ygge (2007) identified that a mixture of novice and experienced nurses give a good working climate and both groups can learn from each other.

nice" meant to them. Some children mentioned health professionals were nice because when they asked for things health professionals responded to their requests promptly. For example, Kerry (13 years) told me that the nurses were "really nice" because they would get her whatever she wanted and John (13 years) stated that nurses were very nice because when he would ask for anything he would get it straight away. Other children, such as Rory (12 years) and Stephen (11 years), relayed that it was the way nurses talked to them that was nice. In the next extract, Chloe portrayed the nurses as being "sound", "bang on" and genuine ("down to earth") because they would talk to her at anytime.

> Chloe informed me that the nurses are "not stuck up" but rather "down to earth" "nice people". For example, she told me that when she walked to the toilet earlier today there was someone in there [toilet] and the nurse had said to her just sit here and wait on the chair in the nurses' station. She reiterated that the nurses "just talk to you anytime" (Field Notes: Informal Conversation: Chloe 16 years: November 2004)

Children valued being spoken to, and acknowledged, as opposed to being ignored. The following conversational field note extract serves to illustrate this point by displaying two contrasting experiences, encountered by Rebecca, when she attended for an ultrasound on two different occasions.

> Rebecca informed me that on the first day, when she went for an ultrasound there was a man, she didn't know what he was called but she stated that he was "ignorant" on this day. She went on to say that this man who was doing the ultrasound didn't say what he was doing and her mother asked him about what he was seen. He told her mother that he couldn't tell her she'd have to talk to the doctor because he couldn't make the decision. Rebecca reiterated "but he didn't even talk to us" and reckoned he was "having a bad day" on that particular day. Rebecca had postulated this because she relayed to me that when she went back down for another ultrasound for "gall bladder", "not really sure what that is" stated Rebecca, the man was "nicer" and "chatted away" to both her and her mother about what he was looking at. (Field Notes: Informal Conversation: Rebecca 11 years: November 2004)

Rebecca equates her first, less favourable, experience to the *ultrasound man having a bad day.* On this day perhaps due to other *"competing demands"* the man pushed Rebecca and her mother to the background by ignoring them and focusing merely on the task in hand, to perform the procedure. On the second occasion Rebecca had a more favourable experience because the same *ultrasound man* was nicer and chatted to her and her mother about what he was doing. The above extract illustrates an isolated instance of a *not so*

*nice* encounter with a health professional. The majority of children talked about *nice friendly* health professionals who talked to them all the time, especially whenever they came into the room or whenever they were passing, as illustrated in the excerpts below.

> Freddie stated that the nurses are very friendly because they talked to him all the time whenever they came in to the room. (Field Notes: Informal Conversation: Freddie 10 years: November 2004)

> Chloe stated that the nurses are all very nice, friendly and always in good form. They [nurses] asked her was she alright, did she need anything and whenever they are passing by her bed they would say hello and ask how she was? (Field Notes: Informal Conversation: Chloe 16 years: November 2004)

The above excerpt expressed by Chloe portrays the repetitious and fleeting nature of being asked, daily and whenever the nurses pass by, *how are you.*

**Drawing 9: Holly 6 years (December 2004)**



This open-ended question, "how are you...feeling", became a noteworthy statement appearing repeatedly in the data. It is portrayed above in Holly's drawing of when the nurse came to see her. However, despite its open-ended nature, in the context of this study, this question, "how are you?" has been labelled a *rhetorical open question*. Initially, on the surface this question *how are you*, appeared to be affectively focused and exploratory in nature, attempting to elicit the child's view of how he/she felt. However, digging deeper and going beneath the surface, this question, *how are you*, was not employed in this fashion. Rather, it was used habitually, without real purpose, like a conversation opener or a greeting such as hello, a question whose purpose was not to obtain an answer, for most people do not care what the response is. The expected response was *fine*. These findings lend support to the seminal work of Macleod-Clark (1981), who reported that although nurses employed open questions when initiating interactions with adult patients, these open questions were not used in a skilled fashion to encourage communication, but rather in a stereotypical way. Also, in describing four levels of interaction, each level based on the degree to which patients' feelings are explored, Faulkner (1998) used the example "Hi, how are you? Fine" to describe the first superficial level, deeming that although this asks the patient how they feel it does so at a social superficial level. However, Byrne and Heyman (1997) urge caution against labelling this *rhetorical open question* as ineffective communication. In doing so, it would fail to recognise its conscious implementation, by nurses, to make their presence known to patients (Chapman, 1983; Byrne and Heyman, 1997). In Byrne and Heyman's (1997) study, accident and emergency nurses, in an adult setting, described "popping in" and "dashing in and out" as strategies to assist them in coping with physical *"competing demands"*. Thus, when health professionals are "busy", perhaps they consciously use this strategy, of asking children how they feel every time they enter the room, as a means of demonstrating to them that they have not been forgotten about.

This is similar to Chapman's (1983) argument that perhaps such ritualistic behaviours as "popping in" may have a symbolic significance, providing the patient with the support of the nurse's presence at regular intervals. Burnard (2003) refers to this as phatic

communication, a term first used in anthropology to describe language used in free aimless social intercourse. Arguable, nurses instigate such language to demonstrate their presence to patients and build friendly social relationships (Burnard, 2003). In this study such an approach would at regular intervals temporarily bring the child to the forefront of the communication process and counterbalance health professionals "busyness". Yet, the prolonged use of phatic communication maintains communication at a superficial level and neglects to identify patient's needs and concerns. This was illustrated in Byrne and Heyman's (1997) study where as a consequence of conflicting physical demands nurses relied on assumptions about patients' anxiety, because they had insufficient time to assess each patient individually. Therefore, while nice, kind and friendly health professionals may create a relaxed social atmosphere and assist in relieving children's anxiety, on the contrary, it could also be viewed as a superficial level of communication that avoids delving beneath the surface to explore deeper emotional concerns.

In summary, this third dimension, *"humanistic qualities"*, of the conceptual extremity "*being at the forefront*", represents one aspect of the *"visible-ness"* construct and one aspect of the *context* in which communication took place between the child and health professional; that is health professionals personal qualities, which were influential in shaping a more facilitative ward ambience. *"Humanistic qualities"* embraces such elements as nice, friendly, humorous and approachable health professionals who despite "being busy" demonstrate their presence to, and acknowledge the presence of, child patients. Owing to the *"humanistic qualities"* of health professionals children were temporarily placed at/moved to the forefront of the communication process.

### **6.4.4.** Summary: *"Visible-ness"*: Context

To summarise, the *context* linked the two opposing dimensions, *"competing demands"* and *"humanistic qualities"*, each of which represents one of the two conceptual extremities of the *"visible-ness"* construct, *"being overshadowed"* and *"being at the forefront"* respectively. *"Competing demands"* captured intrinsic environmental factors central to the children's ward, namely 'busy' health professionals and 'busy' children; which often hindered an effective process of communication. Health professionals

*"humanistic qualities"* counterbalanced these intrinsic environmental factors to assist in creating a ward ambience that was more facilitative in nature. These factors, intrinsic environmental and humanistic factors, determined the extent to which children were involved in the communication process and ultimately the extremity of the *"visible-ness"* construct which the child would occupy.

### 6.5. Conclusion of Findings

In this chapter, the core construct of *"visible-ness"* was presented. *"Visible-ness"* explicates the position the child assumed, the degree to which the child was involved and the extent to which the child's agenda was addressed within the communication process. In order to visualise the abstract construct of *"visible-ness",* it was seen to exist along a continuum with two distinct extremities, *"being overshadowed"* and *"being at the forefront". "Being overshadowed"* referred to the "least" visible position children could occupy within the communication process; that of a passive bystander. *"Being at the forefront"* referred to the "most" visible position children could occupy within the communication process; that of active participant. These two conceptual extremities, *"being overshadowed"* and *"being at the forefront",* were multi-dimensional in nature. The three key dimensions of the extremity *"being overshadowed"* were; *"standing in the background", "left in the dark"* and *"competing demands".* The three key dimensions of the opposing extremity *"being at the forefront"* were; *"invited into the conversation", "being informed"* and *"humanistic qualities"*. All of these dimensions were related to and affected each other. These dimensions were not only connected vertically, according to the conceptual extremity to which they belonged, *"being overshadowed"* or *"being at the forefront",* these conceptual extremities were also connected horizontally, according to the three fundamental elements of the trans-circular model of communication, *process, message* and *context*, all of which collectively influence the effectiveness of the communication process.

The dimensions *"standing in the background"* and *"invited into the conversation"* represented the *process* of communication. The *process* illuminated the degree to which children were involved in the communication process and the extent to which the child's

agenda was addressed. This was determined by the directional flow of the interaction and the communication skills (questioning, listening and reassuring) employed by health professionals. Children physically *"stood in the background"* of the communication process, eavesdropping, when their parent and the health professional interacted together, talking about them in their presence. Children also stood in the background when health professionals restricted their involvement and suppressed their agenda by asking predominantly closed questions, not listening to them and offering premature reassurance. Contrastingly, children were *"invited into the conversation"* when health professionals communicated directly with them, regardless of parental presence, and encouraged their active participation by asking them open ended questions, actively listening to them and offering them an opportunity to ask questions. Both parents and children also actively influenced the position children held within the communication process. Parents blocked their child's positioning at the forefront of the communication process by 'butting in' to the interaction, which took place between the child and health professional. This resulted in children being moved to the background position. Conversely, by initiating interactions with health professionals and 'butting in' to interactions taking place between health professionals and their parents, children invited themselves into the conversation and placed themselves at the forefront of the communication process.

The two dimensions *"left in the dark"* and *"being informed"* represented the *message.* The *message* constituted the information that was exchanged during the interaction *process.* It incorporated such elements as; the amount and type of information exchanged, who exchanged the information, the format in which the information was exchanged and the child's comprehension and interpretation of the information exchanged. Children were *"left in the dark"* when they did not receive adequate comprehensible information. Although, a number of children reported having received some information they felt it was insufficient and superficial in nature. A number of children, mostly, although not exclusively, in the age range 6-11 years, expressed difficulty with understanding complex medical terminology used by health professionals. Children clearly expressed the need for more in-depth, timely, accurate and comprehensible information. There were a small

number of children who preferred to be *"left in the dark"*. These children were not really bothered about getting information, because they did not want to hear bad things. Conversely, *"being informed"* represented children receiving adequate information, explanation, orientation and education, in a comprehensible format. Children valued when comprehensible information came directly to them from the doctor, whom the children regarded as the knowledgeable expert. However, in cases when the doctor neglected to directly inform children, they relied upon the nurse and/or their parent to act as an "intermediary body", transmitting and translating information to and for them. Children provided many examples of health professionals exchanging complex terminology for more easily understandable terms and developmentally appropriate explanations. Children themselves were also active in seeking information and understanding by questioning health professionals, their parents, conversing with other fellow child patients and observing what was going on around them on the ward, thereby influential in moving themselves to the fore of the communication process.

The dimensions *"competing demands"* and *"humanistic qualities"* represented the *context.* The *context* referred to the immediate intrinsic environmental context of the children's ward, in addition to, health professionals' humanistic qualities, which were central to creating the ambience of the internal ward context where communication took place. *"Competing demands"* referred to health professionals and children competing against internal environmental ward demands to communicate with each other. Health professionals were busy and task oriented. They focused on what they were *doing* as opposed to *being* and spending time with children. Although children appreciated health professionals *busyness*, it prevented them from making their presence known (thus from bringing themselves to the fore of the communication process), because they were reluctant to disturb health professionals' busy routine. Similarly, perhaps health professionals were reluctant to disturb *busy children* who were constantly engrossed in play and school activities. The nice and friendly *"humanistic qualities"* of health professionals, through which they demonstrated their own presence and that of the child, helped to counterbalance their *busyness* and created a light hearted ward atmosphere that was more facilitative in nature.

Conceptually presenting the data as a *"visible-ness"* construct, with two extremities and multiple dimensions, I attempted to illustrate the varying experiences reported by child participants, in addition to my observations. There were instances of positive encounters with health professionals and also instances of less positive encounters and ineffective patterns of communication. However, bisecting the data vertically into two conceptual multi-dimensional extremities and rigidly connecting the dimensions horizontally via three distinct headings is problematic. There is the risk of focusing on merely one dimension to the detriment of others. This neglects to recognise the holistic "inter-connectedness" and "over-lapping" of all dimensions. Moreover, the dynamic "fluid-like" complexity of the communication process is not portrayed. The constant movement within and between each dimension is lost. In an attempt to holistically demonstrate the fluidity of this interconnectedness two contrasting patient scenarios, representative of the findings are presented below.

### **6.5.1.** Holistic re-presentation of the two multi-dimensional extremities of the *"visible-ness"* construct

**Scenario 1**

In this first scenario we meet Jane, who occupies the *"overshadowed"* extremity of the *"visible-ness"* construct.[217]

> *Jane (8 years) was admitted to the children's ward with a really bad pain in her side. The doctors had seen her in the emergency department but she couldn't really remember what they had said, they had mostly talked to her mother, but she didn't care because she was too sore and just wanted the pain to go away. Now, the doctor had come to see Jane on the children's ward and she wished he would talk to her and not just her mother. Although he acknowledged Jane by asking her how she was, despite not feeling great, with her pain still niggling a bit, Jane answered politely stating she was fine. The doctor then focused his attention on examining Jane's tummy, pressing in and out and asking is it sore here, and here? Jane heard the doctor tell her mother that she needed to have an operation to remove her*

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[217] The extremity *"being overshadowed"* conceptualises the least visible position children could hold within the communication process. In this position, children were marginal to the communication process, overshadowed by their parents and health professionals.

*appendix. Jane wished they'd talk to and inform her about what was going on and what was wrong with her. She wondered about having to have an operation. She had never had an operation before. She was scared and nervous about what they were going to do, would it hurt? A while later that afternoon, the anaesthetist came and although he did talk directly to Jane it was mainly to ask her a series of closed questions. Furthermore, at times when the anaesthetist was asking her questions her mother interjected not only to answer for her but also to ask the anaesthetist questions. Before he left he said to Jane "don't worry...you'll be asleep". Jane wanted to ask more about her operation but the doctors always seemed in a rush, leaving as quickly as they had arrived.*

The above scenario serves to illustrate Jane occupying a background position in the communication process, which took place between Jane, her mother and the doctor. Jane stood in the background of the communication process because the flow of the conversation was predominantly directed towards their mother. Jane was not communicated with directly by the doctor, but rather the doctor and her mother conversed about her in her presence. Arguably, the doctor did communicate with Jane when he directed closed questions to Jane while examining her. However, this was focused largely on the doctors, not Jane's agenda. Information was relayed to Jane's mother and not directly to Jane. Jane listened in the background and heard she needed to have an operation. As a result, Jane wondered and worried about what was going to happen. Later, when the anaesthetist arrived Jane remained in the background with communication directed mostly to her mother. On occasions when the anaesthetist did attempt to communicate with Jane; Jane's mother interrupted and blocked the interaction. In an attempt to dispel any concerns Jane might have had the anaesthetist prematurely reassured Jane by stating "don't worry…you'll be asleep". Not only did this block Jane's expression of her concerns; it dismissed any worries she may have had. As in Jane's case, the consequence of this marginal position, for children, was that it restricted their involvement in the communication process. Their voice was not heard, nor was their agenda addressed.

**Scenario 2**

In this second scenario we meet Roger, who occupies the *"forefront"* extremity of the "visible-ness" construct.[218]

> *Roger (10 years) was admitted to the children's ward after a serious football tackle which resulted in him breaking his leg. Although he was in severe pain when he arrived at the emergency department he remembers the doctors and nurses attending to him and orientating him to what they were doing. They spoke directly to him asking him about what had happened. While Roger was relaying his story the doctor looked directly at him, stopped what he was doing and in response joked with him about his football skills. The doctor then explained that he thought one of his leg bones might be fractured, which the doctor reiterated just meant broken, but to confirm this he needed to get an x-ray of Roger's leg. Following his x-ray and although Roger's mother had now arrived, the doctor relayed the x-ray result to Roger, confirming to him and showing him on his x-ray that one of the bones in his leg was broken. The doctor went on to explain to Roger that he would need to bring him for an operation to help fix the break. The doctor asked Roger how he felt about having to have an operation. Roger responded saying he didn't know because he had never had one [operation] before. The doctor informed Roger about the operation, what it would be like and what they were going to so. He also told him that after the operation his leg would be in a plaster cast, he wouldn't be able to walk and would need to learn how to use crutches. Then, the doctor provided Roger with an opportunity to ask questions. Roger asked, when would he have his operation, how long would it take and when could he go home.*

In contrast to scenario 1, this second scenario, illustrated above, serves to portray Roger occupying a frontal position within the communication process. Roger occupied a frontal position within the communication process because he was communicated directly with by the doctor. The doctor openly sought Roger's view about what had happened and allowed him to tell his story while he actively listened to what Roger was saying. He incorporated some humour and social chat about Roger's football skills. Despite the presence of Roger's mother he relayed comprehensible information to Roger about what was wrong with him and what the proposed plan of action would be. The doctor explored how Roger felt about having to have an operation and provided him with detailed

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[218] The extremity *"being at the forefront"* conceptualises the position where children were most visible within the communication process. In this position, children were the focal point of the communication process, holding a leading role, with the health professional communicating directly with them, or simultaneous with them and their parents.

information about what was going happen both in theatre and post-operatively. Roger was afforded with an opening to raise issues of concerns to him, by being allocated an opportunity to ask questions. This enabled him to address his own agenda. Like Roger, the implication of this frontal position, for children, was that they felt valued and respected through their inclusion in the communication process. But not only this, the consequence of being included, was that it facilitated being open to children's agenda.

### **6.5.2.** The most optimal extremity of the *"visible-ness"* construct

The inherent difficulty in presenting these two contrasting scenarios, and indeed these two opposing conceptual extremities of the *"visible-ness"* construct, is the risk that either one would be regarded as optimal. For example, scenario one (Jane) would most likely be regarded as an ineffective process of communication, whereas contrastingly scenario two (Roger) would be more likely deemed an effective process of communication. An outstanding question is; where on the *"visible-ness"* construct do children wish to occupy and is there an optimal position or extremity? Is it the *"overshadowed"* or the *"forefront"* extremity? The risk is that the *"forefront"* extremity would be regarded as the optimal position/stance to hold. However, as emerged in this study, not all children want to occupy the frontal position at all points in times. At some particular times and for some particular situations, children are happy to remain in the background, overshadowed by their parents. For example, illustrated briefly at the beginning of scenario one above, when Jane was overshadowed initially she did not care, because she just wanted to get rid of her pain, but later on when she was overshadowed again, at a different point in time, she wanted to be at the forefront.

There were not only variations among/across different children; there were also variations within each individual child, depending on the situation. There were times when children occupied the background and there were other times when these **same** children occupied the forefront of the communication process. Children did not exclusively occupy a frontal or background position in the communication process. Instead, they were in constant motion, back and forth, between the two extremities, *"being overshadowed"* and *"being*

*at the forefront"*. Numerous factors, namely related to the health professional, child, parent and environment, presented under the three distinct heading, *process, message* and *context,* accounted for this constant oscillation between the fore and background (see Table 7).

**Table 7: Factors Influencing Children's Oscillation between the two extremities of the *"Visible-ness"* Construct**

| HEALTH pROFESSIONAL | Child | Parent | Environment |
|---|---|---|---|
| **Directional Flow of the Interaction**<br>▪ To child or parent<br><br>**Communication skills**<br>▪ Closed/open questioning style<br>▪ Effective/ineffective listening<br>▪ Offering Premature Reassurance<br>▪ Inviting child to ask questions<br><br>**Information provision**<br>▪ Amount<br>▪ Comprehension<br>▪ Developmental appropriateness<br>▪ Status of health professional<br>▪ Doctor 'knowledgeable expert'<br>▪ Nurse as intermediary; transmitting and translating information<br><br>**Humanistic Qualities**<br>▪ Nice, friendly, humorous, approachable<br>▪ Presence | **Child self-initiation**<br>▪ Child initiating interactions<br>▪ Child butting in<br>▪ Child asking health professional questions<br>▪ Child asking parent questions<br>▪ Interacting with other children<br>▪ Observing what's happening on ward<br><br>**Age/maturity**<br>▪ Younger or older<br><br>**Previous experience/condition**<br>▪ Acute or chronic<br>▪ Regular attendee or not<br><br>**School**<br>▪ Primary/secondary | **Parental presence**<br>▪ Parent 'butting in'<br>▪ Parent as intermediary; transmitting and translating informati | **Internal: ward context**<br>▪ Busy task oriented health professionals<br>▪ Busy pre-occupied children<br><br>**External: children in society**[219]<br>▪ Construction and re-construction of children in society<br><br>▪ Influential documents e.g. United Nations Convention Rights of Children, National Children's Strategy, Health Strategies/Frameworks |

[219] I will develop environmental factors external to the immediate context of the children's ward, nominally the construction and re-construction of children in society further in the next discussion chapter.

The activation of these factors determined the extremity of the *"visible-ness"* construct children occupied and ultimately regulated the degree to which children were included and visible, or not, in the communication process.[220] What is important to consider is how these factors can be flexibly activated to meet the individual needs of children, depending on which extremity they wish to occupy, at any particular point in time.[221] This highlights the need to consider **both** the *"overshadowed"* and *"forefront"* extremities of the *"visible-ness"* continuum in unison, as opposed to **either** the *"overshadowed"* **or** the *"forefront"* extremity in isolation. Integrating both extremities recognises that children's positioning within the communication process does not remain static at one extremity or the other, rather children move between the two extremities depending on numerous oscillating factors (see Table 7). Considering both extremities as two parts of a whole, rather than two separate parts in opposition, acknowledges that there might be times/situations when children want to be full participants in the communication process but there might also be times/situations when children do not want to be fully involved in the communication process. Thus, it is vital to simultaneously appreciate the relevance of **both** the *"overshadowed"* **and** the *"forefront"* extremities of the *"visible-ness"* continuum, one extremity should not take precedence or be considered more or less effective/important than the other. This emphasises the need to and importance of developing strategies for assessing and re-assessing children's communication needs in order to determine children's individual preferences at any given point in time.

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[220] For example, health professionals are influential in activating the directional flow of the conversation or the type of questioning employed. If health professionals directed conversation towards children but employed closed questions, this would position children at the *"overshadowed"* extremity, whereas if health professionals directed conversation towards children, used open ended questions and gave children an opportunity to ask questions, children would reside at the *"forefront"* extremity of the *"visible-ness"* construct. Children can activate their own movement towards the *"forefront"* extremity by self-initiating interactions and 'butting in' to conversations taking place between health professionals and their parents. Parents can activate children's movement towards the forefront (by acting as an intermediary body) or background (by 'butting in' and interrupting interactions taking place between children and health professionals) extremity of the *"visible-ness"* construct.

[221] For instance, how do health professionals decide when to use closed or open questions, when to direct conversation towards children or their parents and when and how much information to relay to children? How can children be encouraged to ask questions? How can parents by facilitative, but not over-inhibitory, within the process? Answers to all these questions ultimately depend on what individual children want in order to meet their communication needs.

In the next chapter, the implications of these findings will be discussed at a broader and more in-depth level in an attempt to explain why health professionals positioned children **either** at the *"overshadowed"* extremity of the *"visible-ness"* continuum **or** the *"forefront"* extremity of the "visible-ness" continuum. Following these discussions, a new model will be presented, entitled the Child Transitional Communication (CTC) Model, in an attempt to challenge this **either or** thinking by recommending, as child participants in this study desired, the simultaneous consideration of **both** the *"overshadowed"* and *"forefront"* extremities of the *"visible-ness"* continuum.

# CHAPTER 7: DISCUSSION

## 7.0. Introduction

The findings of this study demonstrated that the nature of communication for children admitted to a specialist children's hospital (the KidZ hospital) conceptually mirrored a multi-dimensional *"visible-ness"* construct. Relevant existing research and communication theory was incorporated into the preceding chapter (six) in order to put the findings in context for the reader. However, Dixon-Woods, Young and Heney (2005) argued the literature on communication with children is mostly under-theorised. Therefore, this chapter aims to expand the debate further by examining the implication of the findings at a broader and more in-depth level in an attempt to explain why health professionals positioned children **either** at the *"overshadowed"* **or** the *"forefront"* extremity of the "visible-ness" continuum. It is argued that the findings of this study could be a product of the state of transition of thinking surrounding the social construct of childhood, namely the debate centering on whether children are seen as "human beings" and/or "human becoming" (James, Jenks and Prout, 1998; Uprichard, 2008). This will highlight children's cultural positioning within society, and the tensions this raises. A key question to ask is; how are children thought about and understood? As James, Jenks and Prout (1998:196) contended: "the territory of childhood is populated with persuasive ideas that have, through time, burdened us with a particular vision of the child". The particular childhood image we adopt influences the way we act towards children (Stainton-Rogers, 2001). Kehily and Montgomery (2003:222) raised the question: "how far are children seen as immature, developing human beings, who need protection, or as competent participating social actors?" It is within these debates that this discussion is anchored. In this chapter, six distinct but interrelated subject areas will be explored; (1) children as human "becoming" and/or "being" (2) rights negotiation: protection versus participation (3) shifting power relations (4) universal progression versus guided participation (5) family-centred care and (6) communication models. During the discussion of these subject areas, I illustrate in italics and inverted commas and/or brackets, like so, *"italics"* (section), the sections and/or dimensions of the findings of this study which link to key points being made.

### 7.1. Children as "Becoming" and/or "Being"

The discourse of the child as "becoming" is not new; having dominated childhood studies prior to the 1980's (James and Prout, 1997), with the "fate of children to be waiting. They are waiting to become adults; to mature; to become competent; to get capabilities; to acquire rights; to become useful; to have a say in societal matters; to share resources" (Qvortrup, 2004:267). Within this perspective, referred to as a deterministic model, the child is seen to be "appropriated" or "taken over" by society, to be trained, to become a competent and contributing member of society (Corsaro, 2005:7). Childhood was referred to as a "transitory phenomenon; we 'grow out of it'; it is routinely disregarded on our way to achieving our proper destiny: adult rational life" (Jenks, 2005:53). This transitory state was evident through various terminologies employed, "a becoming; tabula rasa; laying down the foundations; shaping the individual; taking on; growing up; preparation; inadequacy; inexperience; immaturity, and so on". (Jenks, 2005:8).[222] If we consider the position of the child through this "becoming" lens, then we see the child as being in a state of transition; *en-route* to becoming mature and competent; an adult in the making (Butler, 1996; Uprichard, 2008).

Within this viewpoint, children are subordinate to and passive recipients of adults. Some findings of this study mirror this perspective, specifically the *"overshadowed"* extremity of the *"visible-ness"* construct, in which the child played a primarily passive role, being not so much ignored but marginalised as a result of their subordinate position, awaiting integration into society as adults. Viewing the child as "becoming" could account for the limited involvement of and inadequate exploration of the child's perspective within this study. This provides some explanation why health professionals did not communicate directly with or inform children but instead communicated with and informed his/her parent (see Section 6.2.2 and 6.3.2).

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[222] Interestingly, the importance of and justification for enhancing play was on the basis that it prepared children for their future adulthood (Scarlett et al, 2005).

Uprichard (2008) highlighted two noteworthy issues in relation to this perspective of child as "becoming". Firstly, the ideology of child as "becoming" is future orientated, focusing on what the child will become, a future adult, the next generation. Secondly, this perspective implies that adults are competent while children are not. This view conflicts with modern day perspectives, which advocates for listening to the voice of the child, seeing children as actors and "being" in their own right. Lloyd-Smith and Tarr (2000) maintained that despite the emergent rhetoric advocating for the requisite to listen to children, there are social and cultural influences which attempt to justify reluctance to give children voice based on the premise of age, vulnerability and dependency. Lansdown (1994) pointed out that the presumed 'inherent' vulnerability of women was an excuse for failing to address their 'structural' vulnerability. In a similar vein, viewing the child as "becoming" places greater emphasis on children's 'inherent' vulnerability as opposed to their 'structural' vulnerability.[223] This view of the child as "becoming" equates with societal belief of imposing protective limitations upon children; heavily influenced by and derived from historical attitudes and presumptions about the nature of childhood (Lansdown, 1994). Rooted within the seminal work of Aries (1962:31) was the contention that no concept of childhood existed within the Middle Age.

> "Medieval art until about the twelfth century did not know childhood or did not attempt to portray it. It is hard to believe that this neglect was due to incompetence or incapacity; it seems more probable that there was no place for childhood in the medieval world."

Aries illuminated the change over time of how adults recognise, represent and form relationships with children. Essentially two historical images of childhood existed; namely, children as 'innocent and wholesome' and children as 'wicked and sinful' both of which were powerful in emphasising the requisite for adults to protect and control children (Montgomery, 2003).

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[223] Lansdown (1994) describes vulnerability as two-fold, nominally inherent and structural vulnerability. Inherent vulnerability refers to the biological fact of children's physical and cognitive immaturity, which renders them dependent upon adults. Structural vulnerability refers to children's lack of political and economic power and lack of civil rights in society.

Firstly, children were seen as 'innocent and wholesome' within the romantic discourse of childhood. Aries described the 'coddling' view of the 16th century, which portrayed childhood as a happy time with children protected and allowed to enjoy childhood before facing adult responsibilities (Aries, 1962; Stainton-Rogers, 2003; Montgomery, 2003; Corsaro, 2005). This equates with James, Jenks and Prout's (1998) conceptualisation of the innocent child. The adult has responsibility to bring up the child in a manner that preserves his/her state of innocence. This discourse implies to parents, and others, adults have a responsibility to protect children's innocence and ensure that childhood is a happy carefree time (Stainton-Rogers, 2001). Secondly, children were viewed as 'wicked and sinful' within the puritan discourse of childhood. Described by Aries as the 'materialistic' view of the 19th century, childhood was seen as a time of immaturity where children were in need of training/education, control and discipline in preparation for adulthood (Aries, 1962; Stainton-Rogers, 2003; Montgomery, 2003; Corsaro, 2005). This equates with James, Jenks and Prout's (1998) conceptualisation of the evil and immanent child. The parents/adult controlled the evil child by exercising discipline and punishment. This saved the child from his/her own "worst excesses" by contracting him/her into society or family (James, Jenks and Prout, 1998). The immanent child is a partially formed adult who becomes *rational* through education (James, Jenks and Prout, 1998). The "becoming" child is in need of training and socialisation into society by more mature knowledgeable adults. This discourse implies to parents, and others, that adults' have and should use their authority over children to civilise them (Stainton-Rogers, 2001). This view constructs children as incompetent, ignorant and dependent on adults to control and protect them.

When the two discourses, child as sinful and child as innocent are used as an explanatory lens to view the findings of this study through, we are provided with a potentially plausible explanation for the background *"overshadowed"* position that the hospitalised child was placed within the communication process. Adults (health professionals and parents) within this study could have held the view that it was their responsibility to protect the child, thus did not burden the child with involvement (Section 6.2.2) and/or information (Section 6.3.2) because of their perceived vulnerability, innocence,

dependency and incompetence, all of which influenced the level of social engagement between children and adults. This equates somewhat with Myra Bluebond-Langner's (1978) seminal thesis, The Private Worlds of Dying Children, in which a guarded approach was taken in relation to disclosing diagnosis to chronically ill (leukaemia) children aged 3-9 years. Health professionals controlled interactions to protect children from distress. This was also evident in this study whereby sometimes health professionals avoided communicating directly with, disclosing information to and exploring emotional issues with children. Instead they suppressed children's attempts to express their views and concerns by providing them with premature reassurances - the latter possibly considered more palatable than taking the risk that the child would become upset if they were provided with direct information. Furthermore, in some instances when children were communicated directly with, this was controlled by health professionals using closed questions or relaying superficial information. Instances of parents 'butting in' may also mirror their views of children/childhood. It could be likely that this strategy was employed because parents perceived their child as "becoming", part of, or belonging to them, and thus felt that communication should take place between them and health professionals. Jenks (2005:53) commanded:

> "We must shift our perspective to another site. Childhood is not a brief physical inhabitation of a Lilliputian world owned and ruled by others; childhood is rather a historical and cultural experience and its meaning, its interpretation and its interests reside within such contexts."

The social meaning of childhood within western society began to be questioned in the 1980s, with previous dominant accounts of childhood challenged. A new sociology of childhood emerged, heavily influenced by the rise of social constructivists and interpretive perspectives. This brought with it such rhetoric as child as 'social actor' and active 'social agent' (James and Prout, 1997, Corsaro, 2005; Dixon-Woods, Young and Heney, 2005; Uprichard, 2008). James, Jenks and Prout (1998:207) proposed that new discourses of childhood recognised children as "being" with the child "conceived of as a person, a status, a course of action, a set of needs, rights or differences – in sum, as a social actor". Building on this view of children as social actors, James and James (2004:214) asserted:

> "Children are not just social actors, playing a multitude of roles in relation to the increasing range of adults with whom their lives mesh, as they move through their

> own childhoods towards adulthood. They are also social agents in that they shape those roles, both as individuals and as a collectively, and they can create new ones that alter the social space of childhood to be inherited by the next generation."

Similarly, Moosa Mitha (2005:380) maintained:

> "Children may not be responsible for the way the world is and they may not have the psychological wherewithal to make "rational choices" but they certainly respond, mitigate, resist, have views about and interact with the social conditions in which they find themselves."

Within this perspective the drive is to recognise children as active citizens with the ability to act on their own world (Dixon-Woods, Young and Heney, 2005). Children are now seen as interactive social agents, worthy of inclusion alongside adult social groups, appreciated for their current presence; "being" in their own right, and separated from the institutional context of their family (James, Jenks and Prout, 1998; Alanen, 2000; Dixon-Woods, Young and Heney, 2005). Findings from this study lend support to this contention with the *"forefront"* extremity of the *"visible-ness"* construct portraying instances of the child as active participant. Viewing the child as "being" could account for the enhanced involvement of, and exploration of the child's perspective, as evident in the dimension *"invited into the conversation"* (Section 6.2.3). If we consider the position of the child through this "being" lens then the child would be seen in a state of "being" in his/her own right. This provides some plausible explanation of why health professionals were often observed communicating directly with children and provided them with information, either in their parents' presence or absence, as evident in the dimensions *"invited into the conversation"* and *"being informed"* (Sections 6.2.3 and 6.3.3 respectively). Furthermore, children demonstrated their autonomous ability when they self-initiated interactions, asked questions, 'butted in' to interactions between health professionals and parents and invented terminology to describe things they did not possess medical terminology for. In doing this, children altered the directional flow of the conversation and influenced their own level of involvement in the communication process.

This new alternative sociology was in direct contrast to the previous dominant views in which children were viewed as adult in the making; becoming human and adult; and not

being human and child (Dixon-Woods, Young and Heney, 2005). Within this new paradigm, emphasis was placed on the need to recognise children as more than merely passive products of biological processes (James, Jenks and Prout, 1998; James and James, 2004) with notions of universality and normality rejected (Dixon-Woods, Young and Heney, 2005). Instead of a precursor to society, children were now regarded as part of society, active participants in the social construction of a diversity of childhoods (James and James, 2004). The importance of exploring and listening to children's perspective on the social world and studying children in their own right was stressed (Prout and James, 1997). James, Jenks and Prout (1998:207) argued children should not be seen as universally weak, wordless or ignorant and consequently do not have "to be approached from an assumed shortfall of competence, reason or significance".

Although generally attractive, the application of this perspective, child as "being" raises some concerns, namely the risk of completely displacing the image of the developing child with the image of the child as active social actor and agent. Dixon-Woods, Young and Heney (2005) cautioned against this and maintained there is a tendency for the new social studies of childhood to forget that children are also "becoming". In doing this, there is an inherent risk that perceptions of children's general competency to participate may be taken as normative prescription/assumption (or forced participation as described by Marshall (1997)). Taking this to the extreme, it would assume that all children want to be active participants at all levels, with complete responsibility transferred to them. The findings of this study do not lend support to such contentions. For instance, within the dimension *"invited into the conversion"* (see Section 6.2.3) it was illustrated that there were times when children preferred to occupy the background position of the communication process. In some situations, children may not be ready or able to accept complete responsibility and still require the support of their parents. Children as social agents acquire a new set of responsibilities (Jenks, 2005). This new respect for children should not diminish adult responsibility. Instead, it should place alternative responsibility on adults to guide and enable children's social participation (Woodhead and Faulkner, 2000). Marshall (1997) contended that to do this, adults (parents and professionals) may need to be taught how to listen to children and seek their opinions without charging full

responsibility to them. Embracing the discourse of the child as "being" on its own will merely act as a mirror of the child as "becoming". Not only does this reinforce and sustain the hierarchical adult-child dualism, "being" in isolation neglects the child's future aspirations of "becoming" an adult; the temporality of the "becoming" child has been lost (Uprichard, 2008). When we focus on the child as "becoming" we are future oriented. When we focus on the "being" child we are present oriented. Yet, consideration must be given to the past, present and future, for as Emirbayer and Mische (1998:963) highlighted human agency is:

> "A temporally embedded process of social engagement, informed by the past (in its habitual aspect), but also oriented toward the future (as a capacity to imagine alternative possibilities) and toward the present (as a capacity to contextualise past habits and future projects within the contingencies of the moment)."

Jenks (2005:10) expressed similar sentiments, "when we talk of the child we are also talking about recollections of time past, images of current forms of relationships and aspirations toward future states of affairs." Thus, an inherently indispensable part of childhood 'growing up' and 'aspiration of one's future' should not be overlooked (Qvortrup, 2004). It is important to acknowledge that children do become adults and the sorts of adults they are likely to become are shaped by the kinds of childhoods they experience today (Uprichard, 2008). Furthermore, as Jenks (2005:3) contended, "the child, therefore, cannot be imagined except in relation to a conception of the adult, but essentially it becomes impossible to generate a well defined sense of adult and indeed adult society, without first positing the child".[224] Hence, we must consider the child as both "being" and "becoming" together and not necessarily as conflicting discourses but ones that complement each other. Uprichard (2008) argued considering the child as both "being" and "becoming" would increase the child's agency in the world, whereas both approaches used in isolation was problematic. What this represents is potentially two contrasting views of childhood; that of whether children are "becoming" and/or whether they are "being". This highlights the social ambiguity surrounding childhood (James, Jenks and Prout, 1998; Prout, 2000; Jans, 2004). Consequently, there appears to be a long-standing dichotomy of conflict. On one hand, children are objects of protection with

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[224] This links with the concept of family-centred care in which the child and parent are considered one single entity.

adults inclined to cherish and protect them by surrounding them with care. On the other hand, children are encouraged to act as autonomous individuals with their own rights.

This ambiguous dichotomy presents challenges for health professionals when communicating with children as reflected within the dualistic findings of the *"visible-ness"* construct of this study. The two extremities of the *"visible-ness"* construct may help to explain the two different perspectives regarding adult behaviors in relation to children's competence to communicate (see Sections 6.1.1, 6.1.2 and 6.5). The *"overshadowed"* extremity essentially captures the concept of the child as "becoming" with adults, health professionals and parents, instigating strategies, such as communicating with parents as opposed to the child, asking child predominately closed ended questions, employing premature reassurance, not informing the child and parents 'butting in' interrupting interactions between child and health professional, in an attempt to protect the child. Conversely, the *"forefront"* extremity encapsulates the concept of the child as social actor, with adults, health professionals and parents, instigating behaviors, such as directing conversation directly to the child, giving the child a say, asking the child open ended questions, listening to the child and informing the child, that recognise children as "being" in their own right. Furthermore, children demonstrated their own agency through self-initiating interactions and 'butting in' to conversations, which took place between their parents and health professionals, to have their say and ask questions pertinent to their agenda. Arguably children's adoption of medical terminology, of which the meaning they often did not understand, and their invention of terminology to describe things for which they did not know the medical terms, was children's attempt to draw attention to their agency.

As previously mentioned, there is the need to view children simultaneously as "becoming" and "being"; each taking account of protection and autonomy respectively. By combining both, "becoming" (protection) and "being" (autonomy), it would acknowledge or take account of times and situations when children might not want to fully participate. This was evident within this study when a small number of children highlighted that sometimes they preferred to reside in the background of the

communication process (see Sections 6.2.3 and 6.3.3). This illustrates that these children did not necessarily want to be active participants all of the time. At some particular times and for some particular situations, children were happy that the communication took place between the health professional and their parents and they were not really bothered about receiving information. Hence, if we solely consider the extreme view of children as social actors and agents in their own right we neglect to address the times when children may prefer to be regarded as "becoming". It was evident from this study that there were times when children valued the presence and support of their parents (see Section 6.3.3). When health professionals communicated directly with children alongside their parent, perhaps health professionals saw the child through the lens of both "being" and "becoming". They considered the child as "being" in his/her own right, thus they involved and communicated with the child. However, because they also communicated with the child's parent, they also regarded the child as "becoming", thereby valuing parental support. Perhaps this provides some explanation for health professionals not communicating directly with children, without the presence of their parents, because they considered the child to be in need of parental support. However, one important point to deliberate upon is the concept of choice regarding participation in the communication process. It was noted that it was not always the child's preference to occupy the *"overshadowed"* extremity of the *"visible-ness"* construct. In most cases, it was health professionals, and sometimes parents, who placed children in this background position. Therefore, when we combine the view of child as both "being" and "becoming" we must be cautious that the "becoming" child will not supersede the "being" child. A key question to contemplate is; how can we consider the temporality of the "being" child alongside that of the "becoming" child without falling into the dominant protective trap?

### 7.2. Rights Negotiation: Protection versus Participation

One of the difficulties faced by the new sociology of childhood has been the establishment of a clear demarcation between what claims to be new theoretical understanding of children and the discourse of children's rights; the two being intricately interconnected (King, 2007). Stainton-Rogers (2001) proposed recasting the two aforementioned discourses of the 'innocent' and 'sinful' child as the discourse of

'welfare' and 'control' respectively. What is common between these discourses is a concern for children, with adults having a responsibility towards children. If we consider these discourses from a rights perspective, arguably the child does hold rights - of basic welfare and protection (Jenkins, 1993; Lloyd-Smith and Tarr, 2000). However, thinking about the two aforementioned viewpoints, child as "becoming" and/or "being", within a rights-led approach, we are not only faced with welfare/protection concerns. More precisely two predominant contrasting perspectives emerge; most notably, participation and protection, both of which are expressed within the UNCRC (Lansdown, 1994; Marshall, 1997), to which Ireland ratified in 1992.

Both of these concepts, protection and participation, present a real conflict that health professionals and parents must address when involving children in the communication process. Viewing the child as "becoming" or "being" reflects tensions that exist between the need to protect and safeguard, while simultaneously respecting the child's right to participate (Charles–Edwards, 2003). In the context of the two multi-dimensional extremities (Section 6.1.1) of the communication process found to exist in this study, it is argued that the *"overshadowed"* extremity of the *"visible-ness"* construct mirrors debates surrounding the need to protect children because children are seen as "becoming". Contrastingly, the *"forefront"* extremity mirrors debates advocating for children's participatory rights because children are seen as "being" in their own right. As Burr and Montgomery (2003) highlighted, various models of children's rights exist and how we understand rights has an impact on how we support them.[225] Essentially, within rights debates, three key mind-sets exist, protectionist, liberationists and pragmatists (Jenkins, 1993).

Child protectionists define children's rights in terms of their 'not-yet-adults' status. They believe viewing children as equal participants, results in allocating them too many responsibilities beyond their capabilities (Moosa-Mitha, 2005). While this view may

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[225] In agreement, Marshall (1997) contended that "attitudes of mind" towards children's participation is principle to the successful operation of the UNCRC (1989). Kilkelly and Donnelly (2006) contended that a lack of understanding of children's rights was an influential factor affecting children's participation in healthcare.

seem paternalistic, some would argue that such a view is acceptable because "children have not yet developed the cognitive capacity to make intelligent decisions in light of relevant information about themselves and the world" (Burr and Montgomery, 2003:149). Others would argue that constructing children as incompetent excludes them, controls them and emphasises their dependency on adults for protection (Dixon-Woods, Young and Heney, 2005). Regardless, these rights are decided and enforced by adults whereby the child is constructed as a 'subject' in need of adult protection (Jenkins, 1993). Therefore, if health professionals and parents were to consider rights from a protectionist standpoint they would expect society to impose protective limitations upon children (Rushforth, 1999; Burr and Montgomery, 2003).

Considering the findings of this study through this protectionist viewpoint, perhaps health professionals and parents saw themselves as carers with responsibility to protect children from harm. For instance, possibly parents butted in to interactions between their child and health professional in an attempt to protect and shield their child from information (Section 6.2.2 *"standing in the background"*). This also could account for why health professionals choose to withhold information from children, predominantly relaying information to the child's parents (Section 6.2.2). Such a strategy allows parents to serve as gatekeepers of information pertinent to their child's health allowing them to choose the amount and type of information that they share with their child. Findings from Evans's (1994) study lends some support to this view, where one mother expressed the belief that in order to avoid child anxiety communication between the nurse and mother should not take place within earshot of the child. In Lewis et al's (2007) study, which explored children, parents and nurses experience of working in partnership in an acute care setting, children expressed a desire for their parents to make decisions on their behalf and to protect them from hearing distressing information. This lends support to some children in this study who preferred to be *"left in the dark"* (Section 6.3.2).

It would appear that health professionals and parents assume *protective* responsibility for children. Indeed, the role, rights and duties of parents in respect of their children are

clearly expressed within protectionist articles of the UNCRC (1989).[226] One of the Conventions primary underlying principles is the consideration of the "best interests" of the child in all actions that concern them.[227] Acting in the best interests of the child means that adults who act on behalf of children should always place the child's welfare and best interest above other considerations (Burr and Montgomery, 2003). Yet, *acting in the child's best interest* could be viewed as a powerful tool which adults use to justify suppressing children's wishes and feelings; perpetuating the structural vulnerability of childhood (Lansdown, 1994). Although children's right to hold an opinion and to be consulted about their future is enshrined within the UNCRC (1989), adults may decide that children's best interests might be better served by not involving or informing them (Burr and Montgomery, 2003). For instance, children may not be involved and information withheld from them with the view that it would place undue pressure, distress or damage upon them (Marshall, 1997). This is a form of nutrient power, exercised by health professionals on behalf of the patient (Martin, 1998b). It equates with Hewitt's (2002) contention that health professionals exercise a form of benevolent paternalism, which despite its best interests restricts patient self-determination.

This line of argument could provide rationale for some of the findings of this study. For example, within the dimension *"standing in the background"* (Section 6.2.2), communication was either directed towards the child's parent or towards the child, but health professional controlled and focused. Similarly, within the dimension, *"left in the dark"* (Section 6.3.2), information was either relayed to the child's parent or to the child, but health professional orientated, superficial and not based on each child's individual needs. Essentially the voice and agenda of the health professional superseded the voice of the child. Did health professionals deem this to be in the child's best interests? Furthermore, within the dimension, *"competing demands"* (Section 6.4.2), the busyness

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[226] For instance, Article 18 states "parents or, as the case may be, legal guardians, have the primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern".

[227] Article 3 states "in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration".

of health professionals, as reported by child participants, could be a means of protecting children. Business could enable health professionals to avoid contact with children, eliminating the difficulty of having to decide what and how much information, if any, they should relay to the child.[228] Others would argue that such language as *'their best interests'* represents a paternalistic philosophy of exclusion dressed up as protection (Oakley, 1994). The danger is that in acting as protector's adults speak for children rather than facilitate children to voice their own perspectives. Here, the focus would remain not in the child as "being" but in the child as "becoming".

Resistance to children's participatory rights may be reflective of a cultural tradition in which children are viewed as 'possessions' or 'owned by' their parents (Jenkins, 1993; Burr and Montgomery, 2003), who were assumed to act in their child's best interests with the child having no rights to independence. Accordingly, possibly parents themselves and health professionals consider parents as responsible for their child or view the child as part of or belonging to the parent; as portrayed through kinship relations such as, 'my child' or 'his/her child' (James and James, 2004). Indeed, up until the 1980's the tendency within sociology was to consider the child as a mere component of his/her parents, immersed within the institutional context of his/her family, as opposed to a unique entity in his/her own right (James, Jenks and Prout, 1998; Alanen, 2000).[229] Oakley (1994) and Mayall (1994; 2000) sought to liberate children from being conceptually subsumed within families.[230]

Liberationists argue that children are imprisoned in childhood, deemed incompetent by adult attitudes. Children must be liberated from this state to be viewed as "being" in their own right (Burr and Montgomery, 2003). Within this perspective, children are viewed the same as adults, equal members of society and entitled to similar rights as adults (Moosa-

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[228] Contentions but forth here about health professional *busyness* require further investigation from the perspective of other stakeholders, nominally health professionals themselves.

[229] Arguably, such a view has been put forward within the health care of children through the philosophy of family-centred care, which will be referred to at a later point.

[230] Oakley (1994) equated the feminist agenda with the child emancipation agenda, in which both children and women were seen as members of minority social groups, deprived of rights and 'hidden in ideological approaches of family'.

Mitha, 2005). Children are not seen as 'waiting' to acquire adult competencies. The belief is that when empowered children can act as a source of expertise, skill and information, and contribute towards meeting their own needs (Burr and Montgomery, 2003). Children are constructed as active 'citizens' holding rights independent of their parents and adults and capable of making decisions on their own behalf (Jenkins, 1993; Lloyd-Smith and Tarr, 2000). Within such a context, arguably, total responsibility is transferred to the child. If health professionals and parents support a participatory or liberationist perspective they would deem it important to involve, listen to and empower children (Rushforth, 1999; Burr and Montgomery, 2003). Such perspectives were evident within the frontal extremity of this study in which health professionals and parents attempted to include children, recognising children's participatory rights. Such participatory rights are expressed within the UNCRC (1989).[231]

The child's right to freedom of expression would appear to be in direct conflict with credence given to adults to act in best interests of the child.[232] In promoting this principle, *best interests*, does it mean that adults will focus solely on children's protective welfare to the neglect of children's participatory welfare? Marshall (1997) argued Article 12 should be freestanding and unqualified and child's right to participate should not be moderated by deliberating best interests. Instead, adults must develop a system, which would appropriately facilitate children's participation. Thus, promoting the principle, *in the best interests,* does not mean solely addressing a protectionist welfare approach, rather a comprehensive rights based approach must be embraced (Lansdown, 2001). For instance, listening to children is important in terms of giving them an opportunity to express their views. However, moving beyond this, listening is also an important element in protecting the welfare of children (Lansdown, 2001; 2003; Thomas, 2001). Respecting the views of children enables and empowers them to acquire confidence to challenge any

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[231] For instance, most notably within Article 12 "state parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child" and Article 13 "the child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information".

[232] See Marshall (1997) for debate on tensions between best interests as expressed in Article 3 and the principle of participation as expressed in Article 12.

abuse of their rights (Lansdown, 2003). Yet, as referred to earlier those who resist rights often see it as giving too much responsibility to children.

It is important to remember that when promoting children's rights it is not about giving a license to children to take complete control of their lives irrespective of their level of competence and/or readiness. Constructing children as participants affords them the right to consultation about important decisions made on their behalf. This does not imply outright acceptance of children's wishes but rather the requirement to consult children (Jenkins, 1993; Lloyd-Smith and Tarr, 2000). Indeed, children themselves, when given the opportunity to rank different aspects of participation in order of importance, consistently choose to have a say and be listened to above to get what I want (Thomas and O'Kane, 1998). Hence, children prefer dialogue to simply getting their own way (Thomas, 2001). In this thesis, children did not converse specifically about getting their own way. Rather child participants highlighted the value they placed on having an opportunity to express their views and be listened to (Section 6.2.3 *"invited into the conversation"*). This was in direct opposition to the dimension, *"standing in the background"* (Section 6.2.2), within which children's views were unexplored and not listened to. Perhaps an explanation for this is the discord faced by health professionals, that of supporting the child's perspective and agenda and/or following their own perspective and agenda. Not only did the dimension *"standing in the background"* (Section 6.2.2) result in children concealing their worries and fears but it made them feel marginalised within the communication process.

Much of the controversy that exists on children's rights (between protectionist and participatory/liberationist perspectives) centers on the issue of children's competence (Burr and Montgomery, 2003). For instance, if children are viewed as "becoming" then they are seen as developing competence by progressing through individual stages of maturation. When we consider the child as "becoming", we start with the presumption of protection and gradually move towards self-determination as the child develops (Lansdown, 1994). A frequently asked question is, at what age does a child become competent to give consent, take part in research, make decisions, make choices about

their lives, be involved, express their opinion, and so on? By debating the age at which children become competent presumes children move from an incompetent state to a state of competency acquiring the necessary capacity to participate (Kilkelly and Donnelly, 2006). There appears to have been a shift from a complete state of incompetence to a complete competent state. Limited debate has centered on how children make this incompetent-competent transition.[233] Findings of this study support this contention and caution against the universal prescription of older age as a determining factor of children's competence to participate in the communication process. In this study, there were instances of marginalisation of older children (aged 12 – 16 years) in the communication process (*"overshadowed"* extremity of *"visible-ness"* construct – see Sections 6.2.2, 6.3.2 and 6.4.2). Furthermore, being of an older age did not mean that these children always wanted to occupy the frontal position of the *"visible-ness"* construct. There were also instances where younger children (aged 6-11 years) were actively involved in the communication process (*"forefront"* extremity of *"visible-ness"* construct – see Sections 6.2.3, 6.3.3 and 6.4.3). Similarly, being of a younger age did not mean that these children preferred to occupy the background position of the *"visible-ness"* construct.

The view that children are progressive in acquiring competence is now challenged, in light of such debates surrounding the rights and status of children (Burr and Montgomery, 2003). An alternative model is to begin with the positive assumption of self-determination (view children as competent rather than incompetent) (Lansdown, 1994; Thomas, 2001). However, would this, beginning with the assumption of the child as competent, run the risk of dismissing how the child progresses in developing competency?[234] Furthermore, does beginning with this assumption of competent children

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[233] This point links with theories of developmental psychology, most notably, Piaget and Vygotsky. In debating, the age at which children develop competence could be equated with the work of Piaget in how children move through development stages. Whereas Vygotsky's work could potentially explain how children move from incompetent to competence, through the support/scaffolding from adults and influence of socio-cultural context. Both these theorists will be referred to later.

[234] This competent-incompetent debate equates with the differing perspectives of the child as "being" and "becoming" respectively. Comparable to the movement of thinking about the child as "being" as opposed

take account of the diversity of competency? For example, in her seminal work Alderson's (1993:158)[235] highlighted the varying facets of children's competencies:

> "Competence is more influenced by the social context and the child's experience than by innate ability and to respect children means we must not think in sharp dichotomies of wise adult/immature child, infallible doctor/ignorant patient, but to see wisdom and uncertainty shared among people of varying ages and experiences."

In the above extract, Alderson (1993) suggests that children's competence is better understood when children's inner attributes are viewed within a nest of relationships and socio-cultural influences. Similarly, Bluebond-Langner, DeCicco and Belasco (2005) proposed that a principle factor influencing children's participation related not to the child's competence but to the social roles and realities of family life. Findings from this study support these contentions by suggesting that when determining children's level of engagement within the communication process there is the need to consider more than merely each individual child's age and competence level. This study established other key factors upon which children's visibility-invisibility in the communication process was contingent (see Section 6.5.2). For example, the presence of parents, children's previous hospital/illness experience, children's exposure to previous family hospital/illness experiences and schooling. Furthermore, children's active participation was hindered not only by the busyness of the health professionals but also by the busyness of children themselves (see Section 6.4.2). Therefore, in promoting active child participation contextual complexities must be considered.

Another difficulty of framing children as active participatory agents alongside competency is, as an elusive concept, competency might not always be a clearly identifiable entity (Minow, 1996). Yet, to comply with Article 12 of the UNCRC someone must assess children's maturity and capability of forming and expressing their views (Marshall, 1997). This determination of children's ability and competence to act as active participants largely rests with adult authority. Thus, it is often a value laden

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to "becoming" there appears to be a complete shift in thinking towards the child as "competent" as opposed to "incompetent" respectively.

[235] Alderson's (1993) seminal work explored children's, parents and health professionals views on the age at which children are deemed competent to consent to orthopaedic surgery.

judgment open to individual adult interpretation (Fulbrook, 1994). This could account for some of the findings of this study, notably the *"overshadowed"* extremity of the *"visible-ness"* construct. Perhaps children were placed within this background position because health professionals deemed them to be incompetence as active participants. As Marshall (1997) contended, for adults to adequately determine children's competence and ability to participate they require training and knowledge in child development and skills for communicating with children. It is worthy to note that this same recommendation put forward ten years later with the current identification of a deficiency in "adequate training and education on children's rights, child development or ways of listening effectively to children in the health care setting" in Ireland (Kilkelly and Donnelly, 2006:89) and in the UK (Health Care Commission, 2007).

As previously highlighted, "being" and "becoming" may not necessarily be conflicting discourses but ones that complement each other. In a similar vein, perhaps it should not be about protection *versus* participation or competence *versus* incompetence. Instead the focus should be on how to achieve a balance between protection and participation and to account for children's diverse competencies and preferences. Pragmatists would see this need to balance both protection and participation (Rushforth, 1999). The findings of this study lend support to this contention with the two contrasting extremities, *"overshadowed"* and *"forefront"*, of the *"visible-ness"* construct reflecting protection and participation respectively. Abstractly conceptualised as a continuum, the two extremities of the *"visible-ness"* construct, *"being overshadowed"* and *"being at the forefront"*, represent two extreme positions children could occupy within the communication process (Section 6.1.1). Rather than viewing **either** position **or** extremity as most effective, it is vital to appreciate the relevance of **both** of these extreme positions. One extremity does not necessarily take precedence over the other (see Section 6.5.2). This was evident in this study when children themselves highlighted that while they wished to be directly involved and communicated with; at times they still required the support of their parents. In some instances children preferred to be at the *"forefront"*, whereas at other times they are happy to remain in the background *"overshadowed"* position (e.g. did not want information or to hear bad things).

Arguably, children's busyness (Section 6.4.2) could be children protecting themselves, not only offering them an escape route for expelling anxiety but also enabling them to refrain from excess involvement with health professionals. Perhaps keeping busy, through the availability of various play and school activities, has become a social defense mechanism for children in hospital.[236] These findings evoke thoughts of the socially constructed defense system described by Menzies's (1961)[237] in her classical work. Debatably this social defense mechanism worked both ways with children's busyness affording health professionals with a legitimate rationale for distancing themselves from their child patients. Therefore, possibly not only was children's busyness a protective mechanism for children, it was also a protective mechanism for health professionals enabling them, through avoidance, to cope with emotional aspects of their work. Alongside busy children were busy task orientated health professionals. Health professional busyness potentially minimised any extensive direct contact they had with children enabling them to maintain communication at a superficial level.

As previously highlighted, children's rights are not only about participation but also protection. For example, the need to take cognisance of the "becoming" needs of children is evident within the UNCRC (1989) where developmental psychology phraseology is embedded (see Article 6, 32, 12) (Woodhead, 2003b). For instance, Article 12 states "in accordance with age and maturity of the child". Essentially this places some restrictions upon children. Furthermore, who is it that decides what is in accordance with child's age and maturity; the adult. While Marshall (1997) contended that the appeal for an element of 'flexibility' sits uncomfortably with the insistence on participation as a right, Jans

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[236] The contentions put forth here must be considered in light of the cultural norm for children to be busy and continually engaged in play and activities, as highlighted in section 6.4.2, and thus is not unique to the hospital setting. However, as highlighted in section 6.4.2 the impact of play, activities and technologies on the communication process, which takes place between children and health professionals in a hospital setting, requires further investigation, in addition to the value of such interventions as a protective mechanism for children in hospital.

[237] Menzies (1961) referred to socially constructed defense systems which nurses employed in an attempt to address their anxiety; the core of their anxiety being the relations they had with the patients. Consequently, nurses split their contact with patients through their busyness and task allocation to protect themselves from anxiety.

(2004) recommended avoiding the unilateral encouragement of child autonomy, stressing the necessity not to lose track of the child's need for protection and support. As mentioned above child's simultaneous need for protection and autonomy was evident within the findings of this study, in relation to children's participation in the communication process.

This supports Moosa-Mitha's (2005:381) suggestion for the need to "examine children's participation within interdependent relationships, rather than in terms of their rights of autonomy that emphasises independence from these relationships". Similarly, Dixon-Wood, Young and Heney (2005) cautioned against the liberation of children as a distinct social group, arguing that this fails to adequately locate children within their families, neglecting the role parents play in co-producing their children's health and how children's experiences are shaped by family context. The debate about whether children are more emancipated when they act independently or with adults was also raised by Hart (1992). Working with adults may be more suitable and effective in some circumstances. Such views are pertinent to the findings of this study. In terms of the communication process, parents acted as an important intermediary between children and health professionals (Section 6.3.3).[238] This does not illustrate that children do not see themselves as "being", they do, because they want to be communicated with and included. However, children also want their parents alongside them, valuing parental support because they recognise that they are also in a state of "becoming". It is a matter of trying to achieve a balance of participation-protection, both of which the UNCRC encapsulates. This is further apparent within the vision of our National Children's Strategy (Department of Health and Children, 2000:4 original italics) which simultaneously advocates for the need to respect children as being in their own right and children's need for family and societal support to enable them to apprehend their potential:

> *"An Ireland where children are respected as young citizens; with a valued contribution to make and a voice of their own; where all children are cherished*

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[238] Examples of role of parent: child asks parent questions, parents help them understand, parents relay information to them.

*and supported by family, and the wider society; where they enjoy a fulfilled childhood and realise their potential."*

It is important to recognise the dual status of children as people now and people for the future (Mayall, 1998), with the emphasis on children as bearer of rights not necessarily excluding the emphasis on children as future citizens. This view is supported by James, Jenks and Prout (1998) who argued that the tendency for autonomy does not necessarily outweigh the tendency for regulation. Arguably debates surrounding rights negotiation of both protection and participation are essentially about determining who holds, or should hold power (Jenkins, 1993). Indeed, the view of "protecting" children is often instigated and employed as a means for "controlling" children. Enhancing children's participation is essentially about shifting power relationships. For the child to move from a "becoming" to a "being" state one could argue that there is the need for a shift in power balances, from adult/health professional to child/patient.

### 7.3. Shifting Power Relations

The fact that adults write about and debate children's rights might be indicative of power relations, which confine children to subordinate roles in society (Taylor, 2000; Robinson and Kellett, 2004). Debatably *rights negotiation* is essentially about determining who holds, or should hold power (Charles-Edwards, 2003), with the UNCRC (1989) said to challenge adult power. In support, Joslyn, Such and Bond (2005) argued that the current emphasis on listening to the voice of the child challenges the belief that adults know best. Powerlessness and lack of control are viewed as domineering features of childhood (Lansdown, 1994). Hegar and Hunzeker (1988) contended that part of children's powerlessness is unavoidable because of their lack of experience, maturity and resources to meet their own needs. While sometimes legitimate arguments are employed out of concern to protect the developing child, in other cases overemphasis on protection is more related to the threat of change and shift in power relationships that conferring rights implies (Charles–Edwards, 2003). Through his seminal work on the changing nature of punishment, Foucault (1991) illuminated how processes established to protect the marginalised often controlled them. Hill et al (2004) suggested that one of the foremost barriers to children's participation is adult's perceptions of children's abilities, in addition

to adult's self-interest in maintaining their position with respect to children. If we are serious about trying to uphold children's rights in practice, then we need to consider how we exercise power and control over children (Charles–Edwards, 2003).

Within the context of this study, power was not solely related to adult-child relations, but also incorporated health professional-patient power relations. This mirrors Parsons historical work on the ideology of the 'adult' patient sick role. Within this theory, Parson's demonstrated that the physician held *power over* patients. Talcott Parson's illuminated how society expected patients to behave when sick, that of a passive recipient of care who conformed to acceptable social obligations and expectations (Parsons and Fox, 1982; Crossley, 1998). When sick patients were stripped of their normal social duties and responsibilities, they placed their trust in the doctor, the knowledgeable expert, who had a duty of care primarily oriented to the patient's welfare. Thus, the prevailing paternalistic ethic of care was that the doctor knew best and the patient was dependent upon the doctor to get well/better. The physician's focus was limited to curing patients' impersonal healthcare issues through the use of his scientific training and technical competence.

Elements of asymmetry of knowledge, expertise and authority were evident at the *"overshadowed"* extremity of the *"visible-ness"* construct of this study. Paternalistic behaviours were displayed within the dimension *"standing in the background"* (Section 6.2.2) when health professionals over-used closed questions and focused predominantly on physical aspects of care. Health professionals controlled the agenda. The child's agenda was suppressed. Health professionals failed to listen to and explore the child's view. Blocking strategies, such as the use of premature reassurance and medical terminology, were employed. Such findings equate with Mishler's (1984) contention of conflicting voices within the doctor patient asymmetric relationship, with the voice of the medical world dominating while the voice of the patient's life-world was suppressed. The passivity of children was further apparent in this study, within the dimension *"left in the dark"* (Section 6.3.2), when children conformed to the medical examination believing that through the examination the doctor would make them better. This passivity was

reiterated by the health professionals providing 'optimistic assertion'. Here, health professionals often routinely informed children that certain practices and procedures were to make them better. This implied to children that to get better they must conform to such interventions. Nonetheless, some of the children in this study were happy to conform to this passivity and believed that health professionals would make them better.

This equates with Foucault's (1991) thinking that power and knowledge are intertwined, with knowledge often justifying power. The medical examination is a classic example of what Foucault articulated as power-knowledge. The examination combined the controlling strategies of hierarchical observation and normalising judgement. According to Foucault (1991:184) the medical examination transforms the individual into 'a case', an object of care, in which "the deployment of force and establishment of truth" takes place. Such contentions were evident within the findings of this study with child informants relaying that the principle reason for doctors to interact with them was in order to exam them; the body shaped the nature of the interaction (Section 6.4.2 *"competing demands*"). During the objective-physical examination the doctor established truths about the child by asking closed health professional focused questions. The child's body was examined, monitored and compared to norms in relations to health and illness. The stethoscope reflected a capillary form of power (Section 6.3.3 *"being informed"* and specifically Sean's drawing number 6 on page 241). The examination became the focus to identify problems/abnormalities (Section 6.2.2 *"standing in the background"* and specifically the interaction between an anaesthetist and Ann on page 186/187). This concept of normalising judgement could also be utilised as a method to consider the *norms* by which children develop not only physically but also cognitively and socially. Could this account for some of the findings of this study? For instance, were children placed in the *"overshadowed"* position because they were viewed in terms of their miniature size to be physically, cognitively and socially inferior? Within the context of this study, the surveillance of the child's body was not only limited to the medical examination. For instance, the children portrayed situations when they were under nursing surveillance. This was predominantly when nurses routinely attended to their *"checks"* or objective-physiological measurements (for examples see Section 6.4.2

*"competing demands"*), but was also evident through the nurse attending to physiological tasks and physical needs of the child patient. Thus, the ultimate focus was on the docile physical body with the neglect of any subjective-emotional aspects of care. This was further clearly portrayed within the nursing assessment documentation (also outlined in Section 6.4.2 *"competing demands"*). What was generally written and thus presumably assessed in relation to communication was the child's physical ability to communicate with any deviations from normal identified, reflected in models of care such as Smith (1995).

More recent models of healthcare emphasis the desire to transfer *power to* the patient, increasing his/her control over his/her own health and illness. Often defined as a process of transferring power or imparting power from one individual to another, the concept of empowerment emerged as a 'buzzword' in the 1990's. In fact, empowering families is promoted as the essence of paediatric nursing care. Several authors recognise the need for a shift to the balance of power in the parent health professional relationship in order to enable families to become actively involved as 'true' partners in the relationship (Valentine, 1988; Fradd, 1994; Coleman, 2002). The focus is inclined to be primarily on empowering parents to take control in caring for their child with health professionals becoming facilitators to parents. Limited work has been carried out on empowerment and the child patient. Hegar and Hunzeker (1988) highlighted the importance of empowering children themselves because a successful outcome of the empowering process would be an active empowering child, who in turn would become an active empowering adult. The principle of empowerment would view children as competent partners in healthcare whose views and concerns are valid (Kalnins et al, 1992). An important aspect of children's empowerment is concerned with the inequity of the power relationship between children and adults (Hagquist and Starrin, 1997). This augments further the inequitable patient health professional relationship. Although Parson's concept of the patient sick role was critiqued for over emphasise on medical authority and neglect of patient agency (e.g. with chronic illness), Parsons retaliated arguing that regardless of type of illness or enhanced active patient participation and responsibility there would inevitably be an asymmetric relationship between the physician and patient (Crossley,

1998). This was because physicians were responsible and accountable for monitoring the state of the health of the population and, furthermore, this relationship took place within a social structure which involved hierarchical positions of power, authority and prestige (Crossley, 1998). Gwyn (2002:73) would concur with this assertion, that one cannot remove the asymmetric health professional patient relationship, contending;

> "To argue against asymmetry in doctor patient relationship therefore misses the point since any attempted adoption of equality would only be a simulation and would leave intact the essential nature of the power imbalance, which is based on specialized knowledge."

The finding of this study would support such contentions. For instance, within the dimension *"being informed"* (Section 6.3.3) children identified an information hierarchy of knowledgeable experts based on status. Perhaps children's expectation of such a hierarchy is not surprising because this is often portrayed as a normative assumption within society. However, this concept of the health professional as expert does not take account of the regular attendee who has developed much knowledge and expertise. This was highlighted by Katie in this study when she reported that she felt student and junior doctors and nurses would not be knowledgeable enough to attend to aspects of her care (Section 6.3.3). Perhaps Katie wanted greater involvement and a more symmetric relationship, thus challenged the normative assumption that health professionals know best. Other children may want to maintain this asymmetric relationship; they may want the health professional to know best, as previously mentioned. This was evident within this study where a small number of children reported that they did not want to know everything; they just wanted to get better (Section 6.3.2). Indeed, the same child may at times value the asymmetric relationship and at other times value a more symmetric relationship. For instance, in Katie's case where she previously challenged the level of expertise of health professionals at another time (within a different situation) when she was involved directly she was not ready for the responsibility (Section 6.2.3).

The use of the term empowerment can prove problematic. This is because often cited within the same definition of empowerment are two contrasting notions; that of imparting power transfer and the vision of an enabling or helping process (see Rodwell, 1996). The ambiguous use of terminology is illustrated in Coleman's (1998), as cited by Smith,

Coleman and Bradshaw (2002:87), definition of empowerment, within the context of family centred-care, in which both 'enabling' and 'taking control over' appear.

> "A reciprocal social process in which individuals and/or communities are helped to participate with competence, to take control over the factors that affect their lives."

Firstly, if the view of empowerment as the relinquishment of power is embraced, it implies that someone holds power which needs to be transferred to another (*power to*). Smith, Coleman and Bradshaw (2006) support such a view contending that in order for children and families to achieve the empowerment outcome of family-centred care they must take some power and control over their situation. Within such a view, which links to the debate on the child as "being", the child would be seen as capable of *being empowered* with responsibility and power transferred to the child. Actually, those concerned with ideas regarding children's empowerment and active participation may feel this represents giving unnecessary and inappropriate responsibilities to children. This view is supported by some of the findings from this study, for instance Katie's scenario referred to earlier.

Secondly, within an enablement context, empowerment is envisioned as a partnership process. Health professionals share *power with* the patient/child. Coleman (2002:87) introduced an interesting concept, that of 'helped to participate with competence'.[239] This supports Rappaport's (1985) contention that competencies are already present in most people and given the appropriate opportunity and assistance these competencies can be developed. Thus, within this context of communication, for children to be empowered existing competencies may need to be developed and perhaps new additional competencies learned. Recognising that children can be helped to participate with competence places emphasis on children's potential abilities, as opposed to their inabilities (Coleman, 2002).[240] Findings from this study suggest that while children want to be involved and participate in the communication process, they also still value the support of their parents. Perhaps the reason behind this was because children recognised

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[239] The process of enabling equates somewhat to the assistance proposed by Vygotsky (1978). Vygotsky (1978) comprehended the child as both active and in need of support.

[240] This is in conflict with Piaget's thinking which often focused on children's inabilities to perform certain tasks, in addition to many nursing models, which predominantly focus on problem identification.

that there were still things that they themselves needed help with. This equates with findings from Kelsey and Abelson-Mitchell and Skirton's (2007) small scale study which explored ten young people's (12-16 years) views on their involvement in healthcare decisions (see also Kelsey and Abelson-Mitchell, 2007). These young people acknowledged the need for support when involved in healthcare decisions. Additionally, the young people highlighted the negative impact that child empowerment could potentially have on parents, arguing that parents may feel *shut out.* This may provide some explanation for why children in this study felt that parents still needed to be involved and informed.

While parents play an important part within the child health professional relationship, a key factor to consider is; how might parent's presence influence the relationship balance? There is an inherent risk that the focus would turn to the parent as opposed to the child, as Parsons and Fox (1982:151/152) contended "above all it means that third parties, notably parents, must play a particularly important part in the situation. It is common for pediatricians, when they refer to 'my patient' often to mean the mother rather than the sick child". This further adds to the complexity of the power relations and was evident within this study with all stakeholders, child, parent and health professional, attempting to address their own agenda. Casey (2006:93) acknowledged that within a partnership approach "responsibility does not have to be shared equally: the extent to which the child family member and nurse are ready for and able to contribute to the partnership dictates changes in responsibilities". Therefore, as Matthews (2006) highlighted health professionals must approach each child individually to determine the level of involvement the child wants and feels comfortable with. This was illuminated within the findings of this study, for example there were instances when children wanted to be fully involved (for example see Section 6.2.3) but there were also instances of when children did not want to be fully involved (see for example see Section 6.2.2).

These study findings support emerging concepts put forward in discourses on physician adult patient treatment decision-making (Charles, Gafni and Whelan, 1997; 1999; Thompson, 2007a&b). In 1997 Charles, Gafni and Whelan promoted the shared decision-

making model as an ideal approach for determining treatment decisions over other models, such as paternalism, informed decision-making and professional-as-agent.[241] Through the identification of five different levels of patient desired involvement, which he contrasted with professional determined levels of involvement,[242] Thompson (2007a&b) added another valuable category, that of non-involvement. Charles, Gafni and Whelan revisited their proposition in 1999 following further analytic thinking and research on the meaning of shared decision-making to women with early stage breast cancer. Now rather than advocating a particular approach (i.e. the shared decision-making approach), Charles, Gafni and Whelan (1999) emphasised the need for more flexibility in choosing the appropriate model so as to respect differences in individual patient preferences. Within their revised framework, Charles, Gafni and Whelan (1999) make explicit the possibility that the decision-making approach used in one patient physician interaction might differ in the next patient physician interaction. Indeed, they further contended that the decision-making approach may not only differ between situations but it may change even within one single situation.

Although this aforementioned work of Charles, Gafni and Whelan (1997; 1999) and Thompson (2007a&b) related primarily to adults and surrounded the concept of treatment decision-making the propositions for diversity and flexibility support findings from this study. Similar to initial suggestions put forward by Charles, Gafni and Whelan (1997), recommending shared decision-making as the ideal model, there is the potential that the

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[241] **Paternalism** equates with Parson's conceptualisation of the sick role, in which the process of decision making would be dominated by the health professional. Within the **informed decision making** model the health professionals' role would be to merely transfer their expertise to the patient who would be the main decision maker. The **professional-as-agent** would see the professional making the decision with the incorporation of the patient's preferences.

[242] The five levels of patient desired involvement identified by Thompson (2007a) were autonomous decision making, shared decision making, information giving/dialogue, information seeking/receptive and non-involvement. **Autonomous decision making** meant that patients had high degree of responsibility for independent decision making (equates with Charles, Gafni and Whelan's informed decision making). In **shared decision making** patients exercised informed choice (equates with Charles, Gafni and Whelan's shared decision making). **Information giving/dialogue** was a two way process in which patients were listened to and heard with honesty and openness (equates with Charles, Gafni and Whelan's professional-as-agent). **Information seeking/receptive** involves an elementary stage of involvement, that of informing (equates with Charles, Gafni and Whelan's paternalism). **Non-involvement** was where patient placed their trust in the health professional's expertise, acknowledging that involvement could be burdensome.

frontal extremity of the *"visible-ness"* construct, in this study, would be regarded as the *optimal* stance to hold (see Section 6.5.2). However, as emerged in this study, not all children necessarily wanted to occupy the frontal position at all points in times. At some particular times, and for some particular situations, children were happy to remain in the background as passive bystanders, overshadowed by their parents. This highlights the importance of including a category of non-involvement, within which patients, like a small number of children in this study, might be happy, at times, to leave the responsibility of the decision-making/communication to the health professional. Children within this study acknowledged their own lack of knowledge and therefore valued health professional expertise. This highlights the need to simultaneously consider the relevance of both the *"overshadowed"* and the *"forefront"* extremities of the *"visible-ness"* continuum, one extremity should not take precedence or be considered more or less effective/important than the other. Considering the relevance of both extremities recognises that children's positioning within the communication process does not remain static at one extremity or the other, rather children move between the two extremities depending on numerous oscillating factors (see Table 7). These findings coincide with other work in which some children reported that they did not want to know everything (Boylan, 2004), some found information overwhelming (Gibson et al, 2005) and some were content when communication was directed to their parent because they feared hearing bad things (Coyne et al, 2006) and sometimes felt too unwell (Kelsey, Abelson-Mitchell and Skirton, 2007). This said, Coyne et al's (2006) hierarchical illustration of seven levels of participation[243] failed to represent the children who did not want to be involved or consulted with for whatever reason. This has implications for children who perhaps, for whatever reason, are not ready to embrace such responsibility, as emerged in this study. Furthermore, in critique of other participatory models (e.g. Hart, 1992[244];

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[243] The levels of participation identified by Coyne et al (2006) were being the main decider (pinnacle of the hierarchy model), shared decision-making, involved in decision-making and being informed/asking questions/expressing a view/being listened to/being heard (all placed at the base of the hierarchy model).

[244] Hart's eight degrees of participation, presented in the form of a ladder, were: manipulation; decoration; tokenism; assigned but informed; consulted and informed; adult-initiated, shared decisions with children; child-initiated and directed; and child-initiated, shared decisions with adults.

Treseder, 1997[245]), Coyne et al (2006:55) stated that the "level of 'child-initiated and directed' participation will be inappropriate in most healthcare decisions because adults need to be available and responsible for the children, especially during illness". Perhaps this quotation is justifiable when referring to degrees of decision-making. However, the risk that such a statement would become a normative assumption must be avoided.

For instance, findings from this study showed that there were times when children self-initiated interactions with health professionals mainly for the purposes of seeking information, which is often regarded as the building block for decision-making (see Section 6.2.3). Furthermore, there are potentially numerous factors that would impact upon child initiated and directed participation, most notably the accessibility, availability and approachability of health professionals as evident within this study (see Section 6.4.2). Moreover, the above quotation has connotations of power and adds to the debate surrounding adult responsibility. Arguably, determining levels of involvement appears to be a simplistic dichotomy, which equates with the amount of power each party (adults and children) holds, or wishes to hold. For example, Thompson (2007a&b) viewed the professional determined levels of patient involvement as existing along a power continuum, moving from a low level of patient power at the paternalistic end to a high level of patient power at the informed decision making end. Similar contentions could be applied to this study. For instance, when positioned at the *"overshadowed"* extremity of the *"visible-ness"* construct children would be seen as possessing a limited amount of power, whereas at the *"forefront"* extremity children potentially possess a greater amount of power. This is not to say that more power is more desirable, for there were times when children in this study preferred to occupy the *"overshadowed"* extremity of the *"visible-ness"* construct (see for example Sections 6.2.3 and 6.3.2).

Extensive literature within healthcare contends that power rests with the health professional. The unequal health professional patient power relationship is largely argued

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[245] Treseder's five degrees of participation, presented circularly, were: assigned but informed; consulted and informed; adult-initiated, shared decisions with children; child-initiated and directed; and child-initiated, shared decisions with adults.

to be a constraining factor to communication, negotiation, collaboration and thus to achieving a more egalitarian partnership model of care. Even within the most balanced relationship, health professionals are deemed to possess *power over* patients, primarily as a direct result of their familiarity with the hospital environment and their specialist knowledge acquired through education and training (Ramos, 1992). In reality, especially within the context of healthcare, when one talks about power relinquishment one is talking about the surrendering of knowledge and expertise.

Within the context of caring for sick children the difficulties health professionals and parents face in their power struggle are extensively documented (see Section 2.2.2). Parents frequently reported the loss of their parental role with control being handed over to health professionals. Yet, parents believed that they knew their child best and would not surrender power passively to physicians (Gibson, 1995; Kristensson-Hallstrom and Elander, 1997). This could explain the aspect of this study where parents 'butted in' to conversations that took place between child and health professionals (see Section 6.2.2). Similarly, nurses often reported their reluctance to relinquish control feeling the need to protect their expert knowledge. They become gatekeepers of knowledge which parents need in order to make informed decisions (Smith, 2002). Similar findings emerged in this study whereby children reported that information was withheld from them (see Section 6.3.2). Possibly nurses did not inform children because they were holding onto to their expert knowledge as power. Even if unconsciously instigated this denies the child any level of independence and self-determination.

Arguably, relinquishing control poses difficulties for nurses not because they do not believe in children's rights but rather because of their belief about being a good nurse (Charles-Edwards, 2003). Such a contention is supported by Street (1995) who suggested that the prevailing belief among nurses was that they are only doing a good job if they are engaged in ceaseless physical activity. Nevertheless, debatably the busyness of health professionals, as evident within the dimension *"competing demands"* (Section 6.4.2) of this study, was a powerful tool against which children had to compete in an attempt to participate in the communication process. For instance, in this study health professional's

busyness affected children's agency when children became reluctant to ask questions and interrupt health professionals because they perceived them to be too busy. Further, this also provides explanation for the overriding focus on physical aspects of care as opposed to emotional aspects of care within in this study. Recently, in a secondary analysis of data,[246] to explore the concept of busyness (lack of time) within the context of nurses' utilisation of research, Thompson et al (2008:542) defined busyness as:

> "An individual perception of internalised pressure created by a situation where there is a shortage of time to accomplish valued work and often results in a reduced energy level. Objectively, it is characterised by much action and motion."

Within this definition two components of busyness, objective–physical and subjective-psychological, are illuminated. More notably, through their identification of a multitude of factors that influenced physical and psychological busyness, or both, Thompson et al (2008) drew attention to the fact that there appeared to be a culture, created by nurses, other groups of professionals and the organisation itself, in which value was placed on the maintenance of a high degree of visible busyness and the accomplishment of observable physical care. A professional identity of being busy was expected and lack of time was viewed as a culturally accepted answer. Therefore, if busyness is being defined and accepted as a normalised part of the healthcare culture then it is not surprising that children within this study recognised this (Section 6.4.2).

With the transition from medical to family centred models of care, Bradshaw (2002) highlighted that it is important to know what it is that needs to be relinquished. She claimed that it is not nursing expertise that should be forfeited, but more precisely the vision that the nurse is the only expert. More importantly, Bradshaw (2002) contended that two pools of expertise must be acknowledged; that of nurse as expert in caring for the sick child, in addition to family as expert on their child. Although this perspective might sit more comfortably with the second part of the definition on empowerment, that of enabling and helping families, it fails to acknowledge a third source of expertise that of the child within the family.

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[246] Data was originally gathered as part of an ethnographic multiple case study which investigated Canadian nurses research utilisation within the context of adult and pediatric pain management (Thompson et al, 2008).

As previously referred to (see Section 6.3.3), children in this study classified health professionals along an information hierarchy. The doctor was viewed as the best and preferred person to relay information; believed to be more knowledgeable and more powerful than the nurse. The doctors' powerfulness was evident in way he/she relayed information through the use of technical medical language. Child participants believed that nurses did not hold a primary/direct information giving role because they would not know the information to transfer and subsequently might relay inaccurate information. Instead the child participants referred to the nurses and their parents as transmitters and translator's of information that had originally being relayed by the doctor. These findings could be reflective of a lack of an open communication culture whereby the role of the doctor was to relay information. Perhaps nurses were afraid to relinquish information other than which was previously given by the doctor. Nurses continued to orchestrate care according to the traditional medical models of care in which they played a role subservient to doctors (Bradshaw, 2002; Hewitt, 2002). This is how the children in this study perceived it to be.[247] Is this deference to doctors an unwritten cultural rule which leads patients to perceive nurses as powerless? Interestingly, in relation to nurses' decision-making role, Lewis et al (2007) reported that nurses' felt that they often indirectly influenced decisions about children's care. However, the nurses believed that this was not always explicitly apparent to children and their parents because it was hidden within their *busyness* image. This created the image of the nurse as supporter for medical staff.

In his thesis, Nursing Power and Social Judgement, set within an adult context, Johnson (1997) reported how nurses' authority for action (in respect of diagnosis/prognosis disclosure) was principally dependent upon the desires of medical staff, in which a degree of uncertainty in terms of nurses' position to medical authority was apparent. It has also been reported elsewhere that doctors prohibited nurses relaying information because they felt threatened by the nurses' advocacy and its encroachment on their information giving

[247] This is also how parents saw the role of nurses, as mediator between the doctor and parent (Espezel and Canam, 2003). The nurse was seen as having an indirect role in information giving.

role (Marshall, 1991). In Wilkinson's (1991) study (adult setting) ward sisters reported having negotiated permission from doctors for nursing staff to discuss diagnosis and prognosis with patients, if requested by the patient. If nurses are deemed powerless and un-empowered, how can they empower children and families (Rodwell, 1996; Valentine, 1998; Coleman, 2002)?

This idea that power can be *'given'* to someone to empower them would be refuted according to Foucault's perspective. If we contemplate Foucault's (1991) proposition to reconsider our thinking in relation to power then perhaps we would move beyond viewing power in relation to, who holds power, or not. Power is not hierarchical but rather relational operating in society (Foucault, 1991). It is inevitable and omnipresent; a network of fluid that flows through bodies (Foucault, 1991). Moreover, according to Foucault (1991), power is not omnipotent, for there is always resistance against it. Thus, power is both repressive and productive, acting upon individuals who in turn act upon others. Embedded within all social relations power is exposed through the course of interactions. Power is not a property possessed but rather a strategy exercised; a network of multiple relations constantly in tension (Foucault, 1991).

> "Power is not exercised simply as an obligation or prohibition on those who "do not have it"; it invests them, is transmitted by them and through them; it exerts pressure on them, just as they themselves, in their struggle against it, resist the grip it has on them" (Foucault, 1991:26/27; Rabinow, 1984:174).

Therefore, instead of considering who has, or does not have power, there is the need to consider how power is structured and functioning within relationships (Street, 1995). Within the context of this study there were times when children were seen to and reported exerting their own power by; self-initiating interactions with busy health professionals; asking health professionals questions; 'butting in' on conversations between health professionals and parents; using medical terminology that they did not necessarily understand; inventing their own terminology for items that they did not possess the proper language for and indeed through their own busyness (for examples see Sections 6.2.3, 6.3.3 and 6.4.2 respectively). It could be further argued that the emergence, growth of and campaign for biopsychosocial and family-centred models of healthcare is representative of a circulating power struggle or resistance to historical biomedical

models of care. Perhaps at this time of transition we are experiencing a "dilemma of helping"[248] (Dunst et al, 1988) and part of this dilemma, within the context of caring for sick children, is whether children are viewed as "being" or "becoming" or both "being and becoming".

### 7.4. Universal Progression versus Guided Participation

The stance of the child as "becoming" was consistent with thinking within an era which was predominately influenced by developmental psychology discourse, with such terms as immaturity, irrationality and incompetence dominating. Within such a discourse, the child as 'being' was devalued with the assumption of 'progression' predominating (Tudge and Hogan, 2005). Emphasis was on 'still developing'; 'becoming' more competent and more autonomous; progressing through universal processes of growth and change towards a more mature adult way of functioning (Woodhead, 2003b). Such *maturation* can be paralleled with the model of the socially developing (socialisation) child (James, Jenks and Prout, 1998), where children were viewed as passive representations of future generations with present tense childhoods suppressed; "childhood is, within socialisation theories, without moment; it finds voice only as a distant echo of what it is yet to become" (Jenks, 1996:10). Within this perspective, children were regarded as immature, irrational, incompetent and asocial with adults being mature, rational, competent, social and autonomous; and it was through the process of socialisation that the child changed to an adult (James, Jenks and Prout, 1998; Woodhead, 2003b; James and James, 2004).

One of the most influential developmental theorists, whose work prevails within children's nurse education and research (Twycross and Smith, 2006) is that of Jean Piaget. Piaget proposed that children think qualitatively different to that of adults (Stainton-Rogers, 2001; Rushforth, 2006). Piaget described a series of four predetermined stages of cognitive development through which he believed children's thinking

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[248] Within a model of enabling and empowering Dunst et al (1988) refer to the "dilemma of helping" as disparity arising as a result of conflict between the traditional medical model of care and the more contemporary enablement model of helping, that promotes active family involvement in healthcare.

capabilities progressed from simplicity to complexity of thought; with the eventual achievement of adult logical competence and rationality (Corsaro, 2005; Jenks, 2005). By proposing these universal stages, age limitations were imposed upon children's thinking and reasoning abilities. Children were "marginalised beings awaiting temporal passage, through the acquisition of cognition skills, into social worlds of adults" (Prout and James, 1997:11). Although Piaget portrayed children as active in construction of their own knowledge, he tended to focus more on what children were unable to do as opposed to what children were able to do with some help. This resulted in descriptions of children's limitations and cognitive immaturity rather than attempting to search for children's sense of meaning (Keenan, 2002). Notwithstanding this, drawing upon Piaget's predetermined stages of cognitive development does allow for assessing whether, or not, a child has reached a particular stage of cognitive development (Stainton-Rogers, 2003; Woodhead, 2003b). However, assumptions are often made about what children are capable of doing, knowing and understanding (Rushforth, 2006). For instance, Bibace and Walsh (1980) closely aligned their proposed theory of children's conceptualisation of illness to Piaget's theory on *cognitive development,* in an attempt to propose level of explanations, which might be appropriate for different aged children. In her seminal work Bluebond-Langner (1978) illustrated the historical tendency to protect children by not disclosing diagnostic and prognostic information to them in order to avoid upsetting them.

These perspectives attach importance to knowing a child's age, and from this, one can then depict what the child will be able to do, know and understand at that particular age. Thus, arguably if one presumes that children of certain ages would be unable to participate and understand because of their immaturity, then this would potentially affect the level of involvement and amount of information that would be disclosed to children within the communication process. This could explain some of the findings of this study. For instance, if health professionals used Piaget's theoretical stages through which to view children then they would see children as universally progressing over time in their development and competence. In the context of this study, if children were viewed in this way then children of a younger age would have been seen as potentially unable to participate in the communication process because of their immaturity. This would

provide explanation for why younger children tended to occupy the background *"overshadowed"* extremity of the *"visible-ness"* construct. However, it does not provide explanation for instances when younger children were involved and informed and where older children were observed being excluded from the communication process. In these cases, perhaps children were not seen as universally progressive or contextual factors were taken into account. Indeed, one difficulty of measuring developmental milestones in isolation of context is that it portrays an image of development happening within the child (Woodhead, 2003b). Similar to pre-sociological images of childhood[249] (James, Jenks and Prout, 1998) the influence of the wider context and socio-cultural world is neglected (Rogoff, 1990; Alanen, 2000). As proposed by Jenks (2005:30) treating children as universal "disenables our understanding of the child's particularity and cultural differences within a particular historical context".

This focus on children's cognitive limitations was challenged, with the argument that in reality children were able to understand far more than Piaget originally claimed (McGarrigle and Donaldson, 1974; Donaldson, 1978; Rushforth, 1999; 2006; Woodhead, 2003a). Donaldson (1978) claimed that the unrealistic designs of Piaget's experiments made it impossible for children to reveal their true competencies because the tasks presented to the children did not make human sense. Another common critic of Piaget's work was his view of the child as a lonely scientist developing initially from the inside in isolation of the social context (DeVries, 2000). If there are doubts, about aspects of Piaget's theory, these must be extended to the application of Piagetian principles to care delivery (Rushforth, 2006). In fact, more recently, in the context of healthcare decision-making, influential work by Alderson and others (see Alderson, 1993; Alderson, Sutcliffe and Curtis, 2006) has demonstrated how children of various ages contribute to decision making. Nowhere has there been as much ongoing debate, about children's capacity to participate, than within the research literature itself, with the most contemporary drive to involve children as co-researchers (see Section 4.1 and for example Kellert et al, 2004). The various levels of involvement of both younger and older children within the communication process were also evident within the findings of this study.

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[249] Evil, innocent, immanent, naturally developing and unconscious child

In contrast to Piaget's work, the Vygotskian perspective, congruent with a pragmatist viewpoint, was recommended as more applicable to guide practitioners' in giving children a voice in healthcare (Rushforth, 2006).[250] A contemporary of Piaget, the Russian psychologist Lev Vygotsky emphasised the socially interactive nature of learning, recognising that children's knowledge construction did not occur in a social vacuum but was socio-culturally constructed (Vygotsky, 1978; Woodhead, 1999; Oakley, 2004). Three central tenets of Vygotsky's theory were socio-cultural context, internalisation[251] and zone of proximal development[252] (Vygotsky, 1978; Oakley, 2004; Corsaro, 2005). Like Piaget, Vygotsky saw children as active explorers of their worlds (Keenan, 2002). However, differing from Piaget, who viewed children as solitary figures in construction of knowledge, Vygotsky believed that from the beginning, the child's social environment was an active force in guiding the development of higher cognitive processes (Rogoff, 1990). Vygotsky placed social factors to the fore contending that children firstly developed from the outside. The child's elementary mental functions (innate abilities) were transformed to higher mental functions (socially transformed products of child's initial endowment) through social interactions (Vygotsky, 1978). Thus, cognitive development resulted from processes which occurred firstly between people[253] and secondly within people.[254] Vygotsky (1978:57) refers to this process of functions which moved from interpersonal to intrapersonal as internalisation.

> "Every function in the child's cultural development appears twice: first on the social level, and later, on the individual level; first *between* people (*interpsychologically*), and then *inside* the child (*intrapsychologically*)."

Through dialectical social interactions and practical activities with others, children acquire new skills and knowledge (Oakley, 2004; Corsaro, 2005). If this approach was adapted to communication with children, children would learn about their illness, hospital and healthcare practices through close interactions with health professionals and parents,

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[250] The new sociology of childhood has similarities with the work of the social constructivist Lev Vygotsky.
[251] Transformation of an interpersonal (social) process to an intrapersonal one.
[252] Recognising the role of experienced learners.
[253] Bodies of knowledge and tools of thought at first exist outside the child in the environment culture.
[254] Development consists of gradual internalisation primarily through language to form cultural adaptation.

both of whom would act as guides. One of Vygotsky's (1978:86) best-known concepts is the Zone of Proximal Development (ZPD); defined as:

> "The distance between the actual development level as determined by independent problem solving and the level of potential development as determined through problem solving under adult guidance, or in collaboration with more capable peers." [255]

Interpreting this definition suggests Vygotsky (1978) believed that to actually discover the relationship of developmental process to learning capabilities, at least two developmental levels must be determined, the child's actual and potential level of development. The aforementioned intra- and inter-mental functions correspond with the actual and potential levels of development respectively. Vygotsky contended that at any one point in time a child functioned at a particular *actual* level of development. Vygotsky (1978:85) also believed that each child is capable of further *potential* development once guided by an experienced other:

> "Over a decade even the profoundest thinkers never questioned the assumption, they never entertained the notion, that what children can do with the assistance of others might be in some sense even more indicative of their mental development than what they can do alone."

This excerpt displays that when children interact with others, they are always a step ahead in their development, than when they are alone (Corsaro, 2005). If we consider the findings of this study, in light of Vygotsky's proposition, it would be vital that children are presented with information at a level within their ZPD. Not only this, what this concept ZPD highlights is two different levels of competency (Holaday, LaMontagne and Marciel, 1994). At one level, children are performing the task or participating independently. At a second level, children can only perform the task or participate when in collaboration with a more experienced other, such as an adult member of that culture. As outlined by Holaday, LaMontagne and Marciel (1994) the ZPD consists of two important dimensions; nominally joint collaboration and responsibility transfer.

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[255] An alternative definition offered by Holaday, LaMontagne and Marciel (1994:15) is "the region of potential mastery lying between the level at which a task can be performed independently and the level at which it can only be performed in collaboration with one who is more experienced."

In considering the findings of this study within the context of these propositions, three levels of competency are apparent. Firstly, to equate with the first level of competency mentioned above, when children were placed, in this study, at the *"forefront"* extremity of the *"visible-ness"* construct arguably they were regarded as competent to participate in the communication process independent of their parents with a level of responsibility transferred to them. This was evident when health professionals communicated directly with the child, sought the child's views, listened to the child and relayed information directly to the child (see Sections 6.2.3 and 6.3.3). Secondly, corresponding to the second level of competency identified above, the findings of this study illustrated instances of when health professionals communicated with children alongside their parents. Children valued the presence of their parents, who often translated information for them and answered their questions (see Sections 6.2.3 and 6.3.3). This illustrates the experienced other, health professional/parent, working collaboratively with the child in an attempt to enhance his/her understanding and involvement in the communication process. Finally, however what is not recognised within the above two competency levels are the instances of when children were not involved or communicated with at all, were communicated with but at a mere superficial level and health professional directed, and instances when children did not want to be communicated directly with (see Sections 6.2.2, 6.3.2 and 6.2.3 respectively). This was when children were in the *"overshadowed"* position. Within this position, children are incompetent or in a state of "becoming". What is lacking form this above debate is who and how one determines children's competency level and does this change over time, and if so how?

Vygotsky did not specify how children and more experienced others could work together within the ZPD. It was Wood, Bruner and Ross (1976) who introduced the concept of scaffolding which became embedded within Vygotsky's theory to explain more specifically the process of how adults and children can work together within the child's ZPD.[256] The term scaffolding describes the type of adult assistance and support provided

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[256] The "scaffolding" process outlined by Wood, Bruner and Ross (1976) incorporated the following six steps: 1. Recruitment of the child's attention on the task 2. Reduction in degrees of freedom in the task to manageable limits 3. Maintain direction to keep the child in pursuit of the objective 4. Mark critical features of the task 5. Frustration control 6. Demonstration.

to children within their ZPD: "a kind of "scaffolding" process that enables a child or novice to solve a problem, carry out a task or achieve a goal which would be beyond his unassisted efforts" (Wood, Bruner and Ross, 1976:90). It is important to note that while the use of the metaphor *scaffolding* might imply a rigid structure or one that does not involve the child, the use of the term within this context includes the notion of continual revisions of scaffolding to respond to children's advancement from novice to experienced (Rogoff, 1990). Scaffolding is an interactive process: "in which adults adjust both the amount and type of support they offer to child, leading to the eventual mastery of the skill being taught" (Keenan, 2002:134). This highlights the need to guide learning according to each individual child's abilities and capabilities (Oakley, 2004). To do this, the adult guide must be flexible, sensitive to the child's need for support and constantly modify his/her behaviour in light of what the child is doing (Holaday, LaMontagne and Marciel, 1994; Turner and Berkowitz, 2005; Renninger and Granott, 2005). As Holaday, LaMontagne and Marciel (1994) suggested the adult functions as a regulatory agent. At first, the adult may need to undertake most of the responsibility and offer many suggestions to the child. Adult prompts will decrease when no longer required, with gradual responsibility transferred to the child (Holaday, LaMontagne and Marciel, 1994; Oakley, 2004).

Within this scaffolding image, the *experienced other* plays a vital role in guiding children to complete tasks they are unable to complete independently. This enables children to reach their level of potential development. Vygotsky believed that children did not necessarily need to be ready to progress but rather should be actively encouraged, offered support and guidance to help them move beyond their current level of ability but still remain within their ZPD. This contrasts with Piaget's view of readiness, where children are *progressing universally according to stages* and there is no point in informing them at particular junctures because they will not understand. Vygotsky (1978) believed it vital to begin by finding out what the child already knows, so that this can form the basis for working with him/her in his/her ZPD to reach an enhanced level of understanding (Holaday, LaMontagne and Marciel, 1994; Turner and Berkowitz, 2005). Vygotsky's theory highlights the need for health professionals and parents not to regard the child as

incompetent but to work alongside (scaffold) the child to enhance his/her understanding and competence. This further highlights the need to be aware of each child's actual level of development; knowledge and understanding so then explanations can be planned and structured to help children reach their potential level of development (Holaday, LaMontagne and Marciel, 1994). This draws attention to the importance of assessment (what the child knows already knows and understands so that can plan communication within ZPD), an aspect of the communication process that appeared deficient within this study (see Section 6.4.2).

Although adult-child interactions can take many forms, Vygotsky (1978) regarded language and dialogue to be an important mediator through which adults transmit to children the rich body of knowledge that exists in their culture (Oakley, 2004). Language emerged as a key factor in this study with variations in the comprehensibility (see Section 6.3.3) and incomprehensibility (see Section 6.3.2) of the information presented to children. Children within this study valued the use of simple explanations that enhanced their understanding and made them feel included. This was in contrast to health professionals' use of technical medical terminology which made children feel excluded and resulted in the misinterpretation of information presented. Arguably, the use of technical medical terminology by health professionals was above/beyond/outside the child's ZPD or, more specifically, no guidance was given to children to assist them to understand the medical terminology employed by health professionals. Conversely, the modification of terminology was an attempt to work alongside the child, within his/her ZPD to assist understanding. Indeed, it is through the transmission and translation of technical information supplied by the doctor that the important intermediary role nurses and parents play was displayed (see Section 6.3.3). In this instance, nurses and parents were both vital in assisting children to enhance their understanding. This illustrates expert others, nurses and parents, working with children in their ZPD to help them reach an enhanced level of understanding.

A point to consider here, which was not addressed by Vygotsky, is the quality of the assistance given to the child (Oakley, 2004). This is important in relation to who is

helping the child to learn and communicating with him/her. Firstly, let us consider the parent. In this study, children, both of a younger and older age, identified that their parents, like themselves, often did not understand what health professionals were talking about (Section 6.3.3). In such instances would parents be best placed to act as the child's helper/scaffold? Thus, in light of this argument it would be vital to consider what is the parent's level of knowledge in relation to the child's condition and what will happen to the child during his/her hospital stay, in addition to how they feel about relaying information to their child. A key factor to consider would be parents' level of knowledge and understanding, in preparation for their role as helper.

Secondly, let us consider the health professional as some of the children in this study believed that junior or training health professionals might not be best placed to converse with them about their illness (see Section 6.3.3). This relates to the information hierarchy alluded to earlier, and is an important factor to consider in relation to who is capable of scaffolding the child. This might relate more specifically to the type of information that needs to be relayed and the type of illness the child has. Furthermore, it is not just about having knowledge of medical terminology and the child's illness, it is also about having the skills to communicate effectively with the child; to work alongside and scaffold the child. This requires the ability to be flexible in using these skills according to individual children.

Vygotsky's socio-cultural theory recognises the child as both "being" and "becoming" by placing emphasis on what the child would be able to do, with some support and guidance through interpersonal interactions; scaffolding. Within this perspective, children are seen as being in their own right, social actors/agents, who also need some assistance from adults. The aim of the adult is to gradually remove the support they provide and gradually transfer responsibility to the child (Holaday, LaMontagne and Marciel, 1994; Greig and Taylor, 1999). Again this links to findings of this study, whereby children wanted to be involved in the communication process, but also simultaneously valued the presence and support of their parent. Vygotsky (1978:3) acknowledged the interplay of the biological individual and the socio-cultural context, stating

> "In order to study development in children one must begin with an understanding of dialectical unity of two principally different lines [the biological and the cultural] to adequately study this process, then an experimenter must study both components and the laws which govern their interlacement at each stage of child's development."

However, Vygotsky's theory is criticised for essentially minimising the emphasis on the role of natural forces in children's development (Wertsch and Tulviste, 1992; Keenan, 2002). Rogoff (1990) contended that Vygotsky simply assumed the availability of natural development as a substrate on which cultural development is built. Indeed, James, Jenks and Prout (1998) cautioned that the socially constructed child runs the risk of abandoning the embodied material child. Converse to Vygotsky, Piaget tended to focus on the individual with limited attention to socio-cultural context (Rogoff, 1990). In light of this Dixon-Wood et al (2005) cautioned against rejecting developmental theory outright for not only has it much to offer, but also, if neglected only a partial account of childhood would be acquired. This is supported by Corsaro (2005) who states that any sociological theory that attempts to explain children's understanding and use of information from the adult world, must consider levels of cognitive development. This view is also supported by Thurtle (2005:167):

> "It is not a case of choosing a psychological approach (hinging on development) or a sociological approach (evaluating groups and social influences) as the interaction of both approaches and different ways of thinking can give a broader and richer view of the diversity of children and childhood."

This need to view individuals, their social partners, and socio-cultural contexts as essential and inseparable within one integrated process was embraced by the American Educationalist Barbara Rogoff (1990). Influenced by the work of Lev Vygotsky, Rogoff (1990) proposed the concept of *"guided participation";* emphasising that both 'guidance' and 'participation' are essential to children's apprenticeship in thinking. According to Rogoff (1990:8) guided participation involved:

> "Children and their caregivers and companions in the collaborative processes of (1) building bridges from children's present understanding and skills to reach new understanding and skills, and (2) arranging and structuring children's participation in activities, with dynamic shifts over development in children's responsibilities."

Four important issues emerge from Rogoff's (1990) proposition of guided participation, firstly, the addition of the word guidance to the term participation. Generally, within the

*participation literature* there is the tendency to refer to the term participation in isolation. Perhaps, this has led to some difficulties, because what it does is neglect the role of the parent or experienced other, placing full responsibility on the child as active participant. Secondly, building on Vygotsky's concept of ZPD, Rogoff placed greater emphasis upon the role of children as active participants, learning from observing and participating with peers and more skilled members of society. This was evident in this study whereby some child participants mentioned interacting with fellow child patients to seek information, learning through the environment by observing what was going on in the ward around them and being active themselves in asking questions, 'butting in' and initiating conversation with health professionals (see Sections 6.2.3 and 6.3.3). Thirdly, Rogoff (1990) emphasised that the key to effective scaffolding is sensitivity to the child's level of development and competence, with sensitive adjustment of support during interactions to enable children to extend their current skills and knowledge to a higher level of competence. The goal is to provide support that both challenges and offers sensitive assistance simultaneously. The interdependency[257] of children and their partners is emphasised; as opposed to viewing children as dependent or independent. Instead of asserting whether children are competent, or not, and attempting to determine how children become competent to participate, it should be about how children grow in competence through participation (Woodhead and Faulkner, 2000). Importantly, Rogoff (1990) highlighted that the evaluation of the need for assistance is not only based on a preliminary assessment, but rather an active ongoing adjustment process changing in light of the emergence of new evidence of readiness throughout the course of social interaction. Fourthly, Rogoff highlighted the importance of not only proximal, explicit, face-to-face interactions, but also the relevance of tacit and distal guidance. Indeed, Renninger and Granott (2005:111) expanded the definition of scaffolding to incorporate

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[257] Indeed, although different culturally, in her ethnographic thesis, which explored the everyday lives of children growing up in rural Bolivia, Punch (1998) argued that the notion of interdependence was a more appropriate way to understand child adult relationships. Punch highlighted that it was inappropriate to consider child adult transition in terms of a linear progression, from dependence/incompetence to independence/competence, because in relation to different context and different people children move in and out of independence/competence and dependence/incompetence.

child self-direction and to take cognisance of additional up-to-date supports, such as technology; referring to scaffolding as:

> "Support for learning provided by a person (or group of persons, text, and software) for another, or for oneself, on tasks that may be novel to all parties and that may include multiple solution paths, or have no known solutions."

This could have implications for considering future support structures for guiding children's participation and using alternative approaches for communicating with children. For instance, the findings of this study revealed that health professionals had to compete against busy children, who were incessantly preoccupied with such technologies as play stations and game boys (Section 6.4.2). Play and activities emerged as a natural component of the children's hospital stay. Children in this study reiterated that they liked to be busy playing and engaged in activities, because it combated their boredom. Curtis, James and Birch's (2007) findings support this, where children confirmed according to cultural norms that they needed to keep occupied/busy to avoid boredom. Thus, interestingly similar to busyness being a cultural norm for health professionals, busyness is also a cultural norm for children.[258]

This raises a number of issues; firstly, the findings of this study illustrated that children in hospital, despite their 'sick role' were continuously engaged in a range of play and school activities, both on and off the ward, which kept them *busy* (Section 6.4.2).[259] Because of children's busyness health professionals had to compete for their attention in order to communicate effectively with them. While notwithstanding the extreme benefits (distraction, combat boredom and reduce anxiety) of such play activities and technologies for children, especially in hospital, the impact of these activities and technologies on child health professional interactions has not been challenged. A key question to consider is; what is the impact of the children's busyness on social interactions and relationships with health professionals? Is it plausible that the time children spend engaged in play and school activities in the hospital ward, negatively impacts the amount of time children and

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[258] As previously mentioned this is not unique to children's hospital settings because it is culturally normal within society today for children to be busy and engaged in play and activities.

[259] This equates with Curtis, James and Birch's (2007) contention that children as a category are denied full access to sick role in hospital.

health professionals spend interacting? Arguably, such activities create an abundance of movement, distraction and noise, which ultimately influences the effectiveness of the interpersonal communication process. Consequently, as children and health professionals engage in their separate activities, both busy at their own thing, they do not have time to communicate and the social interaction process becomes displaced. Subsequently, children are positioned at the background extremity of the *"visible-ness"* construct. But how can we capitalise upon children's busyness culture to manoeuvre them to the forefront extremity of the *"visible-ness"* construct, thus to the forefront of the communication process?

In keeping with cultural norms, the focus of using technologies within the hospital setting has centred on entertaining and distracting children. Such practices evolved historically out of concern for the psychosocial needs of children in hospital. Consequently, it is evident from this study that health professionals may need to develop modes of communication that children will find engaging as the last few years has witnessed a substantial increase in technologies such as game consoles, and the hospital environment is no different (see Section 6.4.2). A recent study of play and technology illuminated the prevalent use of technology among children (aged 4-12 years) in Ireland today (Downey, Hayes and O'Neill, 2007). Downey, Hayes and O'Neill (2007:46) stated technology is "a long-term element, not a passing fashion" of children's lives. Frequently mentioned technologies were TV, video, DVD, computer games, games consoles (Play Station, Game Boy and X Box) and mobile phones. These technologies are similar to those identified within this study. Thus, arguably, innovative modes of communication are required to keep abreast with modern technologies and to enable health professionals to effectively engage with and capture children's interest. There is an opportunity to manoeuvre the application of technology beyond a mere distraction and/or entertainment channel, to incorporate it as an intervention vehicle for communicating with children about their healthcare.

Much of what has been written about technology usage within hospital focuses specifically on technology usage for children's support and coping needs, and

predominantly within oncology (Schneider and Workman, 2000; Bush and Simonian, 2002; Suzuki and Kato, 2003). Possibly the most extensive of these interventions is STARBRIGHT[260] a virtual environment designed to link seriously ill children into an interactive online community in which they can play games, learn about their medical treatment, or talk with other chronically ill children (Battles and Wiener, 2002). The aim of the STARBRIGHT intervention is three-fold; to serve as a social network, to assist with distraction by providing entertainment activities and to provide some appropriate information (Battles and Wiener, 2002; Brokstein, Cohen and Walco, 2002). STARBRIGHT has been evaluated positively for providing sick children with a sense of connectedness to other sick peers, reducing loneliness and withdrawn behaviour and for enhancing children's willingness to travel to hospital for treatment (Battles and Wiener, 2002). Similar initiatives have begun to emulate in Ireland (AitEile and Solas) and the UK (Open Space[261]). In Ireland, AitEile[262] developed as a social network to enable children in thirteen different Irish hospitals to communicate via live chat and video conferencing. It also provides educational and game activities. However, as AitEile could only be accessed through the hospital school and play rooms, another initiative, Solas, emerged with the aim of capturing children with restricted movement and those in isolation (http://www.tcd.ie/childrensresearchcentre/). Like STARBRIGHT, the aim of Solas is to provide a communication network to facilitate children's social connectivity with the outside world while in hospital (http://www.tcd.ie/childrensresearchcentre/). To date, its implementation remains at a pilot stage with the involvement of a small number of children (Hicks, 2007, personal communication). The provision of medical information at an appropriate level for children through multimedia technology is an area for future research, with the argument that children who are more knowledgeable about their medical condition and have a better understanding of treatment show greater/enhanced coping skills. There are some examples of such interventions to educate children about

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[260] A private online network connecting children in hospital in the USA and Canada.

[261] Open Space is a web-based resource to facilitate communication among children with chronic illness (www.openspace.nhs.uk/about/openspace/; www.childrenfirst.nhs.uk. This web site provides information on health and hospital life for different aged children.

[262] Centre for Health Informatics, Trinity College Dublin, in conjunction with a number of children's hospitals and the Children's Research Centre, Trinity College Dublin (http://www.tcd.ie/childrensresearchcentre/).

their health condition (Dragone et al, 2002; Brokstein, Cohen and Walco, 2002).[263] However, the focus of these initiatives has largely been on the psychosocial and educational needs of children with chronic illness. Such initiatives would also be beneficial to children with acute illnesses.

Nonetheless, there have been limited debates about the benefits and limitations of developing and implementing such innovative technology based interventions, to communicate with children about their healthcare. With the growth of technology are children within this era more comfortable communicating through different media than actually verbally interacting? Downey, Hayes and O'Neill (2007) highlighted the generational digital divide in their study where children talked about their role in the household as someone who understands technology and teaches their parents. What impact would the use of technology, as a communication intervention, have on improving communication with children in hospital, if any? Would the increased use of technology, as a channel for communication, erode face to face interaction and communication skills? For instance, while some positive effects of computer game usage on children's cognitive development and autonomy enhancement have been considered, others deliberate that engagement in computer games affects children's sociability within friendships and family interactions and hinders the development of interpersonal skills (Subrahmanyam et al, 2000; Shields and Behrman, 2000; Suzuki and Kato, 2003). Thus, arguable there is the risk that time spent using technology to communicate (educate and inform) with children would displace social human interaction and personal face to face contact. Responsiveness and engagement (interactivity) would be lost. Arguably some effect on social engagement was evident within the findings of this study with health professionals competing with busy children in order to communicate with them (see Section 6.4.2). Within this dimension it was evident that when busy children did not overly respond to health professionals, health professionals tended to withdraw and perhaps reduced their interactions with the child or re-directed the interaction towards the child's parent. Others

[263] Dragone et al (2002) reports on an interactive CD Rom 'Kidz with Leukaemia: A Space Adventure' to educate children about leukaemia and Brokstein, Cohen and Walco (2002) mentions the availability of the following education modules; discovering secrets of spinal fluid, exploring your incredible blood and uncovering the mysteries of bone marrow.

would argue that engagement with game technologies does not impact on social inclusion and rather what is important is adult participation and engagement with children in their games (Fromme, 2003). This has similar connotations to Vygotsky's scaffolding concept. Indeed, arguably the use of scaffolding is often inbuilt within many game technologies with the availability of tutorials to guide people through tasks, thus enabling each person to work at his/her own level and pace. Moreover, many game technologies now incorporate a more interactive role. Children are no longer merely passive recipients but rather take on a more active controlling role. Thus, perhaps the use of play technologies could be capitalised upon as a means of communicating with children in hospital. For as Vygotsky (1978:102) postulated:

> "The influence of play on child development is enormous, a child's greatest self-control occurs in play....the child's greatest achievements are possible through play...and in play a child always behaves beyond his average age, above his daily behaviour; in play it is as though he were ahead taller than himself."

However, the impact, both beneficial and detrimental, of the employment of play technologies as a means of communicating with children about healthcare issues and hospitalisation requires further investigation. Furthermore, the capacity of such technologies to address all components of communication is questionable. For example, within this study children valued the presence of the nice and friendly health professionals (Section 6.4.3 *"humanistic qualities"*). Indeed, Beverley Johnson stressed:

> "Technology will never replace other forms of communication. Open mutually respectful communication between a health care provider and the patient and family is foundation for family-centered care. Technology can complement, but never replace it" (Ahmann and Johnson, 2000:91).

### 7.5. Family-Centred Care

The ultimate core value of family-centred care (FCC) is the recognition that the family is the constant in the child's life and advocates the necessity to embrace caring for the child in the context of his/her family (Smith, Coleman and Bradshaw, 2002; 2006). This essentially places the *family* at the heart of the child's care, which in turn shapes not only healthcare policies and facilities but day to day interactions among health professionals, families and child patients (American Academy of Pediatrics, 2003). This is in stark contrast to the historic exclusion of parents, yet it demonstrates the monumental changes

that have occurred over the past four decades, strengthened through cultural shifts in health reform (Clayton, 2002). The children's hospital where this study took place was committed to the adoption of the FCC[264] philosophy and model of care delivery. However, Thurston and Church (2001) contended that while numerous children's wards embrace the philosophy of FCC, emphasis tends to be on partnership with parents rather than children and parents. Furthermore, espousing to a philosophy, such as FCC, does not mean that it is operational in practice (see Bruce and Ritchie, 1997).

In the context of this study, a number of issues in relation to FCC emerged. These issues could account for the different practices which emerged in this study in relation to communicating with the child. Firstly, in a definition, which they claim encapsulates what FCC means for families, children and health professionals, Shields, Pratt and Hunter (2006:1318) suggested:

> "Family-centred care is a way of caring for children and families within health services which ensures that care is planned around the whole family, not just the individual child / person, and in which all the family members are recognised as care recipients."

Although this definition highlights caring for both *child and family* it has paternalistic qualities in stating that family members are "recipients" of care and that this care is planned "around" as opposed to "with" children and their families. This notion of child-family as passive recipients of care equates with discourses referred to within medical models of care, namely Parson's ideology of the *adult patient* sick role, as previously eluded (Section 7.3). Similar tensions appeared within the National Service Framework (Department of Health UK, 2004) which simultaneously recommended coordinating high quality services *around* the needs of the child and family, while also taking their views into account. Such disparity would seem to be at variance with the notion of negotiated collaboration, deemed central to the FCC philosophy. The *"overshadowed"* extremity of the *"visible-ness"* construct (Sections 6.2.2, 6.3.2 and 6.4.2) illuminates that at times there were elements of paternalistic actions expressed within the communication process of this study, nominally when communication took place with the parent as opposed to

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[264] Reflected both in the hospital visiting policy and ward philosophy as previous outlined in section 5.1.1.

directly with the child. In actual fact such findings are reflective of the writings on FCC in which there appears to be a tendency to overtly refer to the parent, with the position of the child within the context FCC not explicitly stated or explored (see Section 2.2.3). This predominant focus on the parent as opposed to the child was also evident in the FCC philosophy of the research site (see Sections 5.1.1 and 5.2), which read "every child should have the support of his/her parent/guardian", "to encourage parents to actively participate in care" and "we promote holistic family-centred care by supporting parents". Furthermore, on reviewing the admission assessment documentation for Barda Linbh the following sections for completion on the admission of the child were revealed:

**REASON FOR ADMISSION GIVEN BY CHILD'S FAMILY (in their own words):**

**PARENTAL PARTICIPATION**
**Anticipated visiting regime**:

Family's desired participation in care:

The overarching focus on the parent in FCC could provide explanation for some of the findings of this study, most notably, why communication took place with, and information was transferred to, parents' instead of children. Was there an expectation that parents would attend to their child's care and thus their child's communication needs? Within the context of FCC, one interpretation is that it is parents' responsibility to care for his/her child, with the support of and assistance from health professionals. A possible reason why health professionals are reluctant to provide information directly to children is that they view this as the parents' responsibility. There could be a general assumption that it is the responsibility of the parent to decide what to tell his/her child and if an outsider (in this case health professional) were to interfere, this might be viewed as undermining parental authority in addition to harming the parent-child relationship (Marshall, 1997). This could also provide an alternative explanation for why parents 'butt in' to interactions taking place between child and health professionals, viewing it as their responsibility to care for their child, in addition to attempting to acquire the necessity information to enable them to fulfill their parental role and responsibilities in caring for their child. Parents 'butting in' could be a sub-conscious intervention with parental support for their child being an automatic process. This raises difficulties for parents in terms of avoiding taking over for their children. Indeed, health professionals viewed parent intervention as a barrier to children's participation (Darbyshire, 1994; Kilkelly and Donnelly, 2006). Tates et al (2002:115) concluded:

> "The low degree of child participation in the doctor-parent-child triad should not be interpreted as a sign of incompetence on behalf of children, but rather as a consequence of the participants' underlying participation framework. We have to conclude that adult participants play a pivotal role in enhancing or restricting child participation."

While there is consensus on the importance of embracing FCC as a core philosophy in children's healthcare, there appears to be ambivalence of underlying beliefs, assumptions and perspectives across settings. One explanation for this could be the emergence of a number of different FCC frameworks, which fundamentally have different underlying philosophies, namely functional, hierarchical, holistic and continuous (Smith, Coleman and Bradshaw, 2002; 2006). The variety of interpretations of FCC affects its implementation (Bridgeman, 1999). This is not surprising for inevitably different

approaches would be appropriate within different contexts, contingent upon different clinical environmental demands and differing needs of children and their families (Bradshaw and Coleman, 2007). However, often research studies do not distinguish between these different approaches nor do they investigate the perspectives participants are practicing. What the four approaches, functional, hierarchical, holistic and continuous, illuminate are the different potential levels of parental involvement. Next, these four approaches are reflected upon in light of the findings of this study. The role of both the parent and child will be considered.

Within a functional framework, health professionals would lead, often without negotiation, retaining power and maintaining a dominant gatekeeper role within the partnership, whereas parents' would be merely involved in functional care-giving activities (Hutchfield, 1999; Smith, Coleman and Bradshaw, 2002; 2006; Bradshaw and Coleman, 2007). If we view this functional framework largely in terms of a health professional parent partnership, then arguably here the health professional would have limited interaction and negotiation with the parent. This in turn would impact on the parent's care giving role, who would have a limited role in relaying medical information to his/her child; potentially seeing this as the role of the dominant health professional. If we consider the child as part of this partnership then arguably elements of such a functional approach to FCC were operational within this study when children occupied the *"overshadowed"* extremity of the *"visible-ness"* construct. Within this *"overshadowed"* position, health professionals controlled the communication process by focusing on their agenda as opposed to the child and family needs. Indeed, resistance to such an approach was evident in this study through parents and children interruptions of the flow of the interactions, demonstrating both their need for involvement.

The children's hospital, where this study took place, espoused to a holistic FCC framework. Within a holistic framework the health professional respects family members as individuals and collaborates with the child and family as equal partners (Casey, 1995; Hutchfield, 1999; Smith, Coleman and Bradshaw, 2002; 2006). Such an approach was evident in this study when children occupied the frontal extremity of the *"visible-ness"*

construct (Sections 6.2.3, 6.3.3 and 6.4.3). Within this frontal position health professionals involved children directly within the communication process; exploring and listening to their perspectives. Smith, Coleman and Bradshaw, (2002:26) in talking about a comparison between a functional and holistic view stated:

> "It could be suggested that communication is a common feature of both views, but the approaches used differ because the holistic view is more about mutuality and open communication than the functional view."

This could explain some of differences in the findings of this study. The FCC approach (functional or holistic) employed by health professionals would determine the communication approach they used. For example, if health professionals adopted a functional view, then it is likely that they would employ a communication approach that equated with the *"overshadowed"* extremity. Whereas, if staff followed the holistic perspective, which the research site hospital espoused to, then a more open form of communication, which positions the parent and child at the *"forefront"* of communication process would have been evident.

A potential bridge between the functional and holistic perspective is the hierarchical framework. This hierarchical framework acknowledges that different children and their families might want to participate in their healthcare at different levels according to their own choosing (Hutchfield, 1999; Smith, Coleman and Bradshaw, 2002). This equates with the findings of this study when some children identified there were potentially some occasions when they may prefer not to actively participate in the communication process. Conversely, this hierarchical perspective might designate a level to a family with the risk that the summit of the hierarchy would be seen as the optimal level to reach. This suggests that all movement is up the hierarchy, with limited option to return to a lower level of participation (Smith, Coleman and Bradshaw, 2006). This fails to recognise the level of care families wish to give children may vary over time. If we consider this in light of parents, then not all parents might want to participate at all times in the care of their child. There may be times when they prefer the health professional to lead. Indeed, children themselves, within this study, identified that parents did not always know and understand what health professionals were saying. Consequently, there may be times

when parents are able to directly inform and communicate with their child but there may be times when it is more appropriate for health professionals to do this. If we consider children's views, from this study, some children reported that at times they preferred to hear things from their parent. Whereas, other children valued information coming directly from the doctor even if they could not particularly understand it.

In contrast to a hierarchical framework, Smith, Coleman and Bradshaw (2002) proposed a FCC Practice Continuum (Tool) in which families are assisted to move in either direction according to individual needs, thus recognising the different needs of different families and indeed different needs within the same family at different points in time throughout the child's healthcare journey. This also recognises different abilities on the part of the nurse to fully negotiate and be partners in care (Coleman, Smith and Bradshaw, 2003). Essentially the continuum proposed by Smith, Coleman and Bradshaw (2002) focuses on facilitating necessary negotiation between nurses and parents allowing parents to choose their level of involvement in child's care; with parental input varying from being nurse led to sharing equal status and being parent led. Thus, the full spectrum of care (parent involvement, participation, partnership, parent/child led, no involvement) that may be experienced by child/family is embraced (Bradshaw and Coleman, 2007). Parents negotiate with nurses where they wish to be on the continuum, with movement back and forth along the continuum as their child's condition dictates/changes. The study findings would suggest that such a framework would be the most appropriate in respect to health professionals' communicating with children and their family.

### 7.6. Communication Models

Effective communication is integral to the successful implementation of family-centred care (FCC) (Ahmann, 1994; Casey, 1995; Smith, Coleman and Bradshaw, 2002; MacKean, Thurston and Scott, 2005; Corlett and Twycross 2006). This is because communication forms the foundation for some of the key underpinning principles of FCC, for instance, involvement, participation, partnership, empowerment and negotiation. Two key fundamentals to moving the orientation of practice towards a FCC model are the recognition that the family is "the constant in child's life" and "parent-

professional collaboration" (Ahmann, 1994:114). Communication, dialogue, active listening, awareness, acceptance of differences and negotiation are as key features of such collaborative relationships. Therefore, the recommendation is that the philosophy of FCC be utilised in conjunction with a communication model (Ahmann, 1994; Smith, Coleman and Bradshaw, 2002; Coleman, Smith and Bradshaw, 2003).

As outlined earlier (Section 3.2 and Appendix 3), the prevailing emphasis within extant communication models suggested for use within the context of FCC (e.g. LEARN and Nursing Mutual Participation Model of Care) is interactions with parents. This is not surprising considering that, as previously eluded (Section 7.5), the prime focus within the concept of FCC has been on collaborating with parents. This further relates to the definition attributed to *family*. Is the family the parent? Is the patient the parent? It would seem so from Ahmann's (1994) perspective. If Ahmann's (1994) adaptation of the LEARN model[265] was employed, and the parent was viewed as the family or patient, then within this study, the child would be positioned at the *"overshadowed"* extremity of the *"visible-ness"* construct, with communication predominately taking place with the child's parent. However, if Berlin and Fowkes (1983) original interpretation of the LEARN model was employed, with the child viewed as the patient, then the child would be communicated with directly exploring his/her views and conveying information to him/her, thus positioning the child at the *"forefront"* extremity of the *"visible-ness"* construct within this study.

Similarly, if we consider the steps of the Nursing Mutual Participation Model of Care (NMPMC), as proposed by Ahmann (1994), the child would be *"overshadowed"* with communication taking place directly with the parent about his/her child. However if we re-focus these steps on the child, then open ended questions would explore directly with the child how he/she was and what help he/she needed, identifying his/her individual preferences. Arguably, such elements were evident within this study at the *"frontal"* extremity of the *"visible-ness"* construct. In spite of the fact that there appears to be some

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[265] Refer to section 3.2 and Appendix 3 for outline of communication models referred to within this thesis. This section returns to review these models in light of the findings of this study.

similarities with the finding of this study and the LEARN (e.g. listening, explaining, acknowledging and negotiating) and NMPMC (e.g. using open-ended questions, ascertaining parent/patient perceptions and preferences) models of communication, these models were developed by adults for adults and explicitly lack the voice of the child. The *"visible-ness"* construct developed in this thesis is unique in its contribution by representing children's voices. Indeed, some important dimensions, namely environmental contextual influences *("competing demands"* Section 6.4.2) and health professionals' *"humanistic qualities"* (Section 6.4.3), identified by child participants and observed by me in this study, were not explicated within the LEARN and NMPMC models.

If we were to consider Szasz and Hollender (1956) three categories (activity-passivity; guidance-cooperation and mutual participation) in relation to the findings of this study we can also see some similarities. For instance, the *"overshadowed"* extremity of the *"visible-ness"* construct equates with the categories of activity-passivity and guidance-cooperation, in which the health professional dominates and is viewed as the expert, whereas mutual participation resembles elements of the *"frontal"* extremity of the *"visible-ness"* construct. What is interesting about the three categories proposed by Szasz and Hollender (1956), were the model prototypes they mentioned. For example, activity-passivity was said to be not unlike a parent-infant relationship; guidance-cooperation a parent-child (adolescent) relationship; and mutual participation an adult-adult relationship. Szasz and Hollender (1956:587) contended:

> "In an evolutionary sense, the pattern of mutual participation is more highly developed than the other two models of the doctor-patient relationship. It requires a more complex psychological and social organisation on the part of both participants. Accordingly, ***it is rarely appropriate for children*** or for those persons who are mentally deficient, very poorly educated, or profoundly immature." [Bold font and Italics added for emphasis]

As evident within the above quotation, Szasz and Hollender (1956) deemed that children could not be mutually involved in a health professional relationship. What this illuminates is the thinking of an era when children were subordinate to adults and not yet "being". Some of the elements of the dimensions of the *"forefront"* extremity of the

*"visible-ness"* construct of this study contest such contentions. For example, there were instances of both child and family involvement in the communication process within the dimension *"invited into the conversation"* (Section 6.2.3) However, child participants, within this study, were clearly aware of inequitable relationships, not only between themselves and health professionals, but also among health professionals when they conversed about an information hierarchy existing at different tiers according to health professional status (Section 6.3.3). Furthermore, while at times some children wanted more equitable relationships, for example, when children 'butted in' to interactions taking place between their parents and health professionals (Section 6.2.3), at other times they did not necessarily view an inequitable relationship as disadvantageous. Instead, they valued that health professionals knew best and trusted in their expertise to make them better. Thus, they were happy to be passive recipients of care (Section 6.3.2).

Szasz and Hollender (1956) introduced the *mutual participation* paradigm for use with chronically ill adults (see Section 3.2) and suggested that individuals with acute illnesses would adopt a more passive and cooperative role, with the health professional dominating. The findings of this study would suggest differently. For example, within this study there were instances of younger children, acutely ill and with no previous hospital experience, involved and participating in the communication process (Section 6.2.3). Additionally, the findings of this study illuminated that being a regular attendee, with a chronic illness, did not necessarily mean that these children always wanted to occupy the frontal position, and mutually participate, within the communication process (Section 6.2.3 and 6.2.4). Thus, within the context of this study, there did not appear to be distinct differences between children of acute or chronic illnesses, or first or recurrent attendees to the children's ward. However, further research specifically exploring these variables would be required before any definitive conclusions could be drawn.

Moreover, importantly, the mutual participation model does not take account of situations and times when children prefer to adopt a less participative role within the communication process, as illustrated within this study (Section 6.2.3 and 6.3.2). Although, Brody (1980:720) acknowledged that "this [mutual participation] approach is

not intended to force the patient to participate in every trivial decision, nor is it attempt to abrogate the physician's responsibility by placing the patient in a self-care situation". Indeed, Szasz and Hollender (1956) did highlight that different types of relationships would be appropriate for different situations. The main challenge would be attending to any change or movement from one type of health professional-patient relationship to another in the course of treatment. This equates with findings of this study, in terms of, how and what activated children's oscillation between the two contrasting extremities, *"being overshadowed"* and *"being at the forefront"*, of the "*visible-ness"* construct (see Section 6.5.2).

Although Casey's (1995) model more explicitly refers to parental involvement in their child's care, from nursing staff's perspective, key elements of Casey's model were evident within the findings of this study, from the child patient perspective. For example, elements of the three approaches, *communicating/nurse centred: permission; non-communicating/nurse-centred: exclusion; non-communicating/person-centred: assumption*, were evident within the dimensions *"standing in the background"* and *"left in the dark"* (Sections 6.2.2 and 6.3.2). Within these dimensions, a one-way process of communication was manifest, within which the health professional dominated and maintained communication as a superficial level. This resulted in the curtailment of the child's agenda and their exclusion from the communication process. The health professional controlled the exchange of information and focused on his/her agenda. By contrast, elements of Casey's approach *communicating/person-centred: negotiation* also emerged within this study, nominally within the dimensions "*invited into the conversation*" (Section 6.2.3) and *"being informed"* (Section 6.3.3). Within these dimensions, children had an opportunity to voice their subjective views, their participation was actively encouraged and they felt listened to. This illustrated elements of a two-way child-patient focused process of communication. Similar to the LEARN and NMPMC models, Casey's (1995) model does not refer to contextual influences such as *"competing demands"* (Section 6.4.2) and *"humanistic qualities"* (Section 6.4.3), two important dimensions which emerged for communicating with children in this study. In

addition, these models fail to take account of instances when children themselves actively self-initiate interactions and self-navigate for information.

The main focus of Alsop-Shields (2002) *Parent-Staff Model of Pediatric Care* model was also on the parent. Alsop-Shields outlined the two components inherent within this model as, the presence of parents and communication between parents and staff. An explanation for this is that Alsop-Shields saw the parent and the child as a single parent-child unit. Arguably, within this conceptualisation of a single unified parent-child entity (Shields and Nixon, 2004), the child has become lost or *hidden*.[266] This muted voice of the child reflects adult (nurse, parent) dominant power and permits an ongoing inequitable relationship (Bricher, 2000). This is not to devalue the role, position and voice of parents themselves in the care of their sick hospitalised child, because as illuminated within this study child participants valued the presence and assistance of their parents in the communication process. Instead, the aspiration is to ensure "the visibility of children, where they belong, at the centre of paediatric nursing practice" (Bricher, 1999b:454). This is because while child participants in this study valued the presence of their parents, they also felt esteemed when health professionals directly involved them in the communication process. Thus, if we are to consider both child and family within the context of FCC then we need a model of communication that is not just adult (health professional and parent) focused and developed but one that is simultaneously child focused and within which the voice of child can also be heard.

In recognising the crucial importance of communication between children and health professionals, this thesis contributes to this knowledge dearth by exploring and representing children's perspectives on the communication process, as it takes place between them and health professionals in an in-patient hospital setting, thereby building upon Sydnor-Greenberg and Dokken's work. Sydnor-Greenberg and Dokken (2001) proposed a CLEAR (context, listening, empowerment, advice and reassurance) communication model to assist with understanding what children like in their interactions

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[266] Additionally, as argued in the previous section, FCC has predominantly concentrated on the parent, and lacked an explicit and consensual definition of *family*.

with health professionals. Although argued earlier (Section 3.2), that this model was limited (e.g. unknown sample size and limited explication of data collection and analysis strategies), the acronym CLEAR has much similarity with some of the findings of this study. Essentially, it is the dimensions situated at the *"forefront"* extremity of the *"visible-ness"* construct that provide support for concepts within the CLEAR model, nominally, health professionals listening to children (Section 6.2.3), health professionals empowering children by communicating directly with them (Section 6.2.3), health professionals providing children with adequate information (Section 6.3.3) and appropriate reassurance (Sections 6.2.2, 6.3.2 and 6.3.3).[267] While the CLEAR model recognises the child as another partner within the communication process and portrayed what children valued in terms of communication with health professionals, the findings of this study further augment this limited body of knowledge by illustrating how the communicative skills (e.g. listening, questioning, reassuring, informing) health professionals utilise can place children in, and move children between, one of two potential positions within the communication process; that of a passive bystander (*"overshadowed"* extremity of *"visible-ness"* construct) or an active participant (*"forefront"* extremity of *"visible-ness"* construct). For example, health professionals not communicating directly with children, listening ineffectively, offering premature reassurance (Section 6.2.2) and not informing children (Section 6.3.2) places them in the background *"overshadowed"* position of the communication process. As a result, children are socially excluded with their active participation blocked. Consequently, they are less empowered, with their agenda unexplored. Contrarily, children are empowered when health professionals communicate directly with them, listen to them (Section 6.2.3), offer informative and reflexive reassurance (Sections 6.3.3 and 6.3.2). This enables children to feel more in control as active participants with their communicative needs addressed.

Another extremely important facet highlighted in this study and not explicated in the CLEAR model proposed by Sydnor-Greenberg and Dokken (2001) were the times and

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[267] Three types of reassurance emerged in this study, premature (dimension *"standing in the background"*), reflexive (optimistic) (dimension *"left in the dark"*) and informative (dimension *"being informed"*).

situations when some children do not want to be empowered or placed at the *"forefront"* of the communication process or *"visible-ness"* construct. Instead, children prefer to be situated in the background *"overshadowed"* position (uninvolved and uninformed) with communication directed to their parent. The risk with the CLEAR model of communication is that it could lead one to believe that all children want to be communicated with and participate at all levels all of the time. Findings from child participants in this thesis challenge such an assumption (Sections 6.2.3 and 6.3.2). Additionally, the CLEAR model fails to capture those children who actively self-initiate conversations, butt into interactions (Section 6.2.3), and self-navigate for information (Section 6.3.3) to ensure their own level of involvement in the communication process, thus oscillate their own positioning between the *"overshadowed"* and *"forefront"* extremities of the *"visible-ness"* construct.

Finally, although the importance of context was highlighted within the CLEAR model (the letter C of the acronym represented context), its meaning differed to the dimension *context* referred to within this study. Context within Sydnor-Greenberg and Dokken's (2001) CLEAR model referred to children being valued as a whole person and not just a person with a chronic or acute illness. In this thesis, *context* encapsulated the internal environmental context of the children's ward (Section 6.4.2 *"competing demands")* and health professionals' *"humanistic qualities"* (Section 6.4.3), both of which were not explicated within the CLEAR, or other aforementioned, communication models. These two dimensions, *"competing demands"* and *"humanistic qualities",* portrayed the *context* within which communication took place, between the health professional, child and his/her parent. However, in an attempt to interpret and explain the key dimensions, and different positions children occupied in the communication process, broader extrinsic contextual factors, which could explain the dualistic nature of communication for children within the children's ward, were also explored. Thus, within this thesis, *context* was expanded to a broader macro level by exploring external environmental influences, in an attempt to explain why two distinct extremities of the communication pocess were found to exist. In doing this, this thesis offers an embryonic, yet unique, theoretically integrated perspective about communication with hospitalised children. To this end, not

only does this thesis contribute to the scant but emerging body of knowledge on communication practices with children in healthcare, from child in-patient perspectives, it also addresses the lack of theorisation on communication with children in healthcare.

### 7.7. Conclusion

In this chapter, six subject areas, nominally children as human becoming and/or being, rights negotiation, shifting power relations, universal progression versus guided participation, family-centred care and communication models, were explored in an attempt to interpret and explain why two opposing extremities (*"being overshadowed"* and *"being at the forefront"*) were found to exist in the communication process on the children's ward. Respectively, these subject areas drew attention to the following dichotomies (or either/or perspectives): child as family member *versus* child as unique entity (family-centred care Section 7.5); child as powerless *versus* empowered child (shifting power relations Section 7.3); child as immature, incompetent, and dependent *versus* child as mature, competent and independent (universal progression versus guided participation Section 7.4); child as having a right to protection *versus* child as having a right to liberation (rights negotiation Section 7.2); and child as becoming *versus* child as being (child as being and/or becoming Section 7.1).

This thesis argues that these conflicting dichotomies, or either/or perspectives, evident within and across these subject areas, potentially explain the bifurcation of children, in terms of their positioning in the communication process. This is whether children are passive bystanders and occupy the *"overshadowed"* extremity of the *"visible-ness"* construct or active participants occupying the *"forefront"* extremity of the *"visible-ness"* construct. Interpreting the capricious perspectives within these aforementioned subject areas further, one overarching dichotomy was found to exist; that is between the two contradictory discourses of protection *versus* participation (see Appendix 42).

Findings from this thesis suggest that the tensions which exist between these two discourses, protection and participation, are embodied within communicative practices on

the children's ward,[268] because both inform how we view and thus how we interact and communicate with children. For instance, if health professionals and parents view children as becoming, immature, incompetent, dependent and thus in need of adult protection they would position children at the *"overshadowed"* or marginal extremity of the *"visible-ness"* construct (see Sections 6.2.2, 6.3.2 and 6.4.2). Contrastingly, if health professionals and parents view children as being, mature, competent, independent and thus able to exercise their autonomy they would involve children as active participants positioning them at the *"forefront"* extremity of the *"visible-ness"* construct (see Sections 6.2.3, 6.3.3 and 6.4.3). As a result, this protection-participation dichotomy leads to contrasting assumptions about what actually counts as appropriate communication with children, with health professionals working from an **either/or** perspective placing children **either** at the *"forefront"* **or** at the *"overshadowed"* extremity of the *"visible-ness"* construct/communication process.

Possibly this either/or perspective (dual extremities) represents adults attempts to grapple with the increasing drive towards enhanced child participation in all matters that affect them, including healthcare. Those (health professionals and parents) supportive of this drive for a more participatory culture would involve and participate with children in the communicative process *("forefront"),* whereas those not in support of, or uncertain about, this move towards a child participatory culture would resist change and continue to exclude and not participate with children in the communication process *("overshadowed").* Perhaps health professionals and parents are unsure how to deal with enhancing children's participation while simultaneously working to protect children from distress/upset.[269] This highlights a complex transitional[270] process of communication, for children, with a dichotomous contest, between the use of strategies to protect and those to

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[268] For instance, a protective discourse reflects the *"overshadowed"* extremity, whereas a participative discourse is reflective of the *"forefront"* extremity of the *"visible-ness"* construct.
[269] This is an area that requires further investigation as recommended in Section 8.5.3.
[270] I use the word transitional to recognise the temporary and ever-changing state of children's positioning within the communication process/*"visible-ness"* construct, influenced by the temporary and ever-changing state of children's positioning within society in general.

encourage participation, which presents extreme challenges for health professionals, parents and children themselves.

However, there is the need to avoid the view that the protective stance is wholly inhibitory and the participatory stance wholly facilitative. This would be a rather simplistic view because some child participants in this study clearly did not regard protection as constraining but rather as enabling (for example, see Section 6.3.2 where some children did not want information and valued the presence and support of their parents) and other children did not explicitly view participation as enabling but rather as constraining (for example, see Section 6.2.3 where some children were not ready to be included/participate on their own at all times). Thus, in contrast to health professionals operation of an **either/or** perspective, children preferred an individualised approach to enable them to oscillate back and forth along the *"visible-ness"* continuum between the two extremities (*"overshadowed"* and *"forefront"*) depending on the context and their needs at that specific point in time. Therefore, based on these findings this thesis offers support for the simultaneous consideration of **both** participative and protective discourses; with child participants clearly articulating that they simultaneously valued the opportunity to participate in the communication process, in addition to, the presence and support of their parents during this process.

In light of these discussions, the next chapter will present a new model, the Child Transitional Communictaion (CTC) Model. This CTC model challenges **either/or** thinking (i.e. either the *"forefront"* or *"overshadowed"* extremity) and recommends the simultaneous consideration of **both** the *"overshadowed"* and *"forefront"* extremities of the *"visible-ness"* continuum.

# CHAPTER 8: KEY CONCLUSIONS AND RECOMMENDATIONS

## 8.0. Introduction

In chapter seven, I attempted to interpret and explain why two opposing extremities (*"being overshadowed"* and *"being at the forefront"*) were found to exist in the communication process (*"visible-ness"* construct) on the children's ward by drawing on a number of different theoretical perspectives, inherent within a number of pertinent subject areas, namely childhood sociology, children's rights, adult-child health professional-patient power relations, developmental psychology, the philosophy of children's healthcare and existing communication models. In Section 7.6, I disputed the adequacy of pre-existing communication models for representing the totality of the findings and discussions of this thesis. Following on from these discussions, in this chapter, I present a Child Transitional Communication (CTC) Model. This CTC model was enacted in an attempt to portray the fluid, dichotomous and transitional nature of the process of communication taking place on the children's ward and to illustrate how this communication process, at a micro interpersonal level (*"visible-ness"* construct with two contrasting extremities), is potentially influenced by, and interconnected with extrinsic environmental forces at a macro level. In this chapter, I also revisit the operational definition of communication set forth in Section 3.3 and review the accomplishment of this study's aims and objectives, before outlining key recommendations for practice, education, research and policy. First, I consider it necessary to return to review the two theoretical frameworks which guided this study.

## 8.1. Guiding Theoretical Frameworks

The two theoretical frameworks which guided this study were the *circular transactional model of communication* (Section 3.2.1) and the principles of the *ecological model of human development* (Section 3.2.2). Despite the argument that circular communication models are more favourable, replacing linear models, there was evidence of use of the conventional one-way linear model within the findings of this study. A one-way linear process of communication was evident when health professionals communicated directly with children but predominantly employed closed questions; thereby ultimately

restricting children's response (see Section 6.2.2). Health professionals controlled the communication process with no exploration of, or room for, the child patients input. Health professionals' relayed information according to their agenda about what they thought was relevant to tell the child. The child was a passive receiver of this information (refer to Section 6.3.2). Potential explanations for the utility of this linear model was that it was more convenient, easier to employ and allowed health professionals to control interactions especially within the context of a busy task focused environment (see Section 6.4.2). Consequently, the child and his/her communicative needs were at the periphery of care, with the health professional and his/her communicative needs taking centre stage.

Conversely, elements of a circular transactional model of communication were also evident within the findings of this study. A two-way process of communication emerged when health professionals listened to and sought children's opinions through the employment of open-ended questions (for examples see Section 6.2.3). Here, the child's agenda took centre stage. However, some elements of the circular transactional model were completely neglected, most notably validation of understanding[271] (see Section 6.3.2). Although the circular transactional model does move beyond the linear model to take account of contextual issues, both intrinsic and extrinsic, which were important within this study (refer to Sections 6.4.3 and 6.4.2), arguably this model remained somewhat at a linear level. What changed is that it became a two-directional, as opposed to a unidirectional, model. However, when considering the communication process within the context of this study and within the context of caring for children in hospital there is a need to view communication as more than a two-way process. For instance, if health professionals are to communicate with both the child patient and his/her parent(s), then the process of communication expands beyond a mere two to a three-way (or more) process. The trans-circular model of communication does not take account of such a three-way process. This provides us with some explanation for the exclusion of the child in the communication process when his/her parent was present (see Section 6.2.2). Yet, within this study parents presence did not exclusively result in children occupying a

[271] Validation is a specific form of feedback, which establishes that both parties have understood the message exchanged.

background position in the communication process. Thus, there was some evidence of a three-way communication process when health professionals communicated with both child and parent (for example see Section 6.2.3).

As mentioned, the trans-circular model of communication acknowledges that a variety of intrinsic and extrinsic factors can affect the interaction process and distort the transmission of the message. For instance, as evident within the finding of this study interference with the message transfer could be within the sender or receiver (health professional, parent and child) and/or environment. This was clearly illuminated in this study within the dimension *"competing demands"* (Section 6.4.2). Here, both child and health professional were observed as being extremely "busy", both preoccupied with things they were doing (health professionals their tasks and children their play/activities), thus illustrating external environmental influences that may block the passage of the message. Furthermore, children's inner anxieties (e.g. scared, pain) could have potentially influenced their interaction with health professionals. For example, children talked about being scared when doctors came to see them and thought about the examination and how painful it might be (see *S*ection 6.3.2). Another substantial interference to an effective communication process, as illustrated within this study, is the language employed. Two sets of contrasting views were evident within the dimensions *"being informed"* and *"left in the dark"* (Sections 6.3.3 and 6.3.2 respectively), in terms of those children who understood and those who did not for whatever reason.

In spite of the fact that the circular transactional model recognises the importance of contextual influences, as previously argued (Section 3.2.1) the contextual factors it addresses are narrow and uncritical in focus. As a consequence, I drew upon the multi-system principles of Bronfenbrenner's (1979) ecological model of human development because such a multi-systems perspective takes cognisance of broader "macro" societal environmental factors, in addition to the immediate interpersonal communication process at a "micro" level (see Section 3.2.2). However, re-examining Bronfenbrenner's multi-system perspectives in light of the findings of this study it became clear that the circular

nested systems[272] were insufficient to illustrate and adequately explain the nature of communication for hospitalised children. The biggest difficulty was that the nested systems failed to portray adequately the dichotomous conflicts (or the either/or perspectives) inherent within and across the five interrelated subject areas, family-centred care, shifting power relations, universal progression versus guided participation, rights negotiation, and children as becoming and/or being, discussed in chapter seven. This highlighted the need to restructure Bronfenbrenner's cyclical representation of multi-systems in an attempt to portray the fluid, dichotomous and transitional nature of the process of communication taking place on the children's ward.

### 8.2. Child Transitional Communication (CTC) Model

This study constructed the process of communication for hospitalised children as a *"visible-ness"* construct. In an attempt to visually present this abstract construct of *"visible-ness"* to the reader, a continuum was enacted to demonstrate two distinct multi-dimensional extremities, *"being overshadowed"* and *"being at the forefront"*, which children could occupy in their interactions with health processionals. These two opposing extremities, which represented the degree to which children were, or wanted to be, included, or excluded in the communication process,[273] were extensively outlined in chapter six. In an attempt to interpret and explain why two opposing extremities (*"being overshadowed"* and *"being at the forefront"*) were found to exist in the communication process on the children's ward, chapter seven examined the *"visible-ness"* construct by exploring on a number of different subject areas, namely childhood sociology, children's rights, adult-child health professional-patient power relations, developmental psychology, the philosophy of children's healthcare and existing communication models/frameworks (see Sections 7.1-7.6). Within each of these subject areas dichotomous (or either/or) thinking was found to exist, nominally between the discourses protection *versus*

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[272] Bronfenbrenner (1979) described 4 interrelated levels conceptualised as nested systems (micro-, meso-, exo- and macrosystem) each situated inside the next, similar to a set of Russian dolls (Section 3.2.2).

[273] For example, at the *"overshadowed"* extremity children were marginal to the communication process. This resulted in their restricted involvement, their voice not being heard, nor their agenda being attended to. Contrastingly, at the *"forefront"* extremity children were active participants, with health professionals communicating directly with them, or simultaneously with them and their parents.

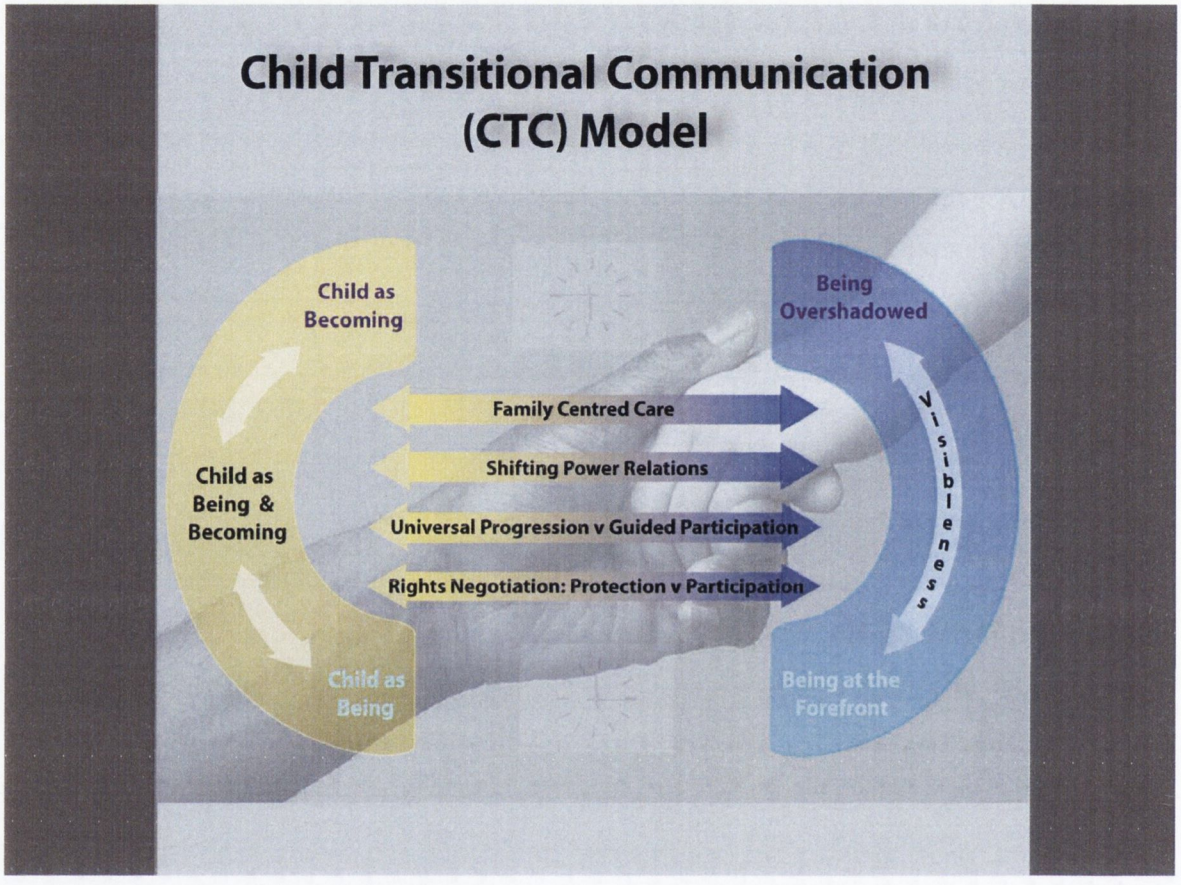
participation (see Section 7.7). This thesis argues that such dichotomous thinking, or **either/or** perspectives, evident within and across these subject areas, could potentially explain the bifurcation of children, in terms of their positioning in the communication process on the children's ward (**either** placed at the *"overshadowed"* **or** *"forefront"* extremity of the *"visible-ness"* continuum). However, the findings of this study highlight the need to appreciate the relevance of **both** the *"overshadowed"* and *"forefront"* extremities because one extremity does not necessarily take precedence over the other. Rather, children oscillate between the two extremities (*"overshadowed"* and *"forefront"*) depending on a number of factors, namely related to the health professional, child, parent and environment (see Section 6.5.2).

Based on these findings and discussions, a unique theoretically integrated communication model, the Child Transitional Communictaion (CTC) model (see Figure 16 below), was developed to challenge an **either/or** approach (i.e. either the *"forefront"* or *"overshadowed"* extremity) to communicating with children in health care by recommending the simultaneous consideration of **both** the *"overshadowed"* and *"forefront"* extremities of the *"visible-ness"* continuum, with neither extremity considered more or less effective/important than the other.

Figure 16 (illustrated below) was designed to provide a visual illustration of how the nature of communication for hospitalised children, at a micro interpersonal process level (*"visible-ness"* construct with two contrasting extremities), is potentially influenced by, and interconnected with extrinsic environmental forces at a macro level. This thesis argues that the process of communication on the children's ward is not impervious to, but rather susceptible to, how children have been conventionally and are contemporary viewed within society, and within the subject areas, family-centred care, shifting power relations, universal progression versus guided participation, rights negotiation and child as being and/or becoming (all illustrated on Figure). The proposition is that the different theoretical perspectives, and how these have evolved over time, inherent within these aforementioned subject areas, situated outside the micro sphere of the proximal

communication process taking place on the children's ward, inevitably impact upon health professional-child communication.

**Figure 16: Child Transitional Communication (CTC) Model**




This Child Transitional Communication (CTC) model attempts to explain why health professionals positioned children **either** at the *"overshadowed"* **or** the *"forefront"* extremity of the *"visible-ness"* continuum. It is proposed that such dualistic positioning of children is representative of the existence of dichotomous thinking, which populates the literature, between the two discourses, protection *versus* participation, both of which are embodied within the extremities *"being overshadowed"* and *"being at the forefront"* respectively. In contrast to health professionals operation of an **either/or** perspective, children preferred an individualised approach to enable them to oscillate back and forth between the *"overshadowed"* and *"forefront"* extremities depending on the context and their needs at that specific point in time. For example, child participants articulated that

they simultaneously valued the opportunity to participate in the communication process, in addition to, having the presence and support of their parents during this process.

In light of this, this thesis challenges the existence and sustainability of contradictory dichotomies/extremities, or **either/or** perspectives, such as being *or* becoming, immature *or* mature, incompetent *or* competent, dependent *or* independent, protection *or* participation, *"overshadowed" or "forefront"* because this would led to the ultimate risk that one side of the dichotomy, or one extremity, would be chosen over another. For instance the *"overshadowed"* (protection) over the *"forefront"* (participation) extremity of the *"visible-ness"* construct. If health professionals were to adopt such a bifurcated stance there is the danger that the child would be placed in a position which he/she did not want to assume and experience negative consequences as a result, as demonstrated by child participants within this study. For example, some children placed at the *"forefront"* extremity of the communication process but did not want to be there and became upset on hearing bad news or frustrated when they felt unable to make a decision for which they were afforded responsibility (for examples see Sections 6.2.3 and 6.3.2). Contrastingly, those children who are placed at the *"overshadowed"* extremity of the *"visible-ness"* construct but wanted to be at the fore were left feeling excluded, uninformed and experienced extreme uncertainty and worried about what was going to happen (see Section 6.3.2).

Furthermore, the findings of this study illuminated that not only were there variations among different children; there were also variations within each individual child, depending on the situation they found themselves in (see Section 6.2.3). For example, on some occasions a child wanted to occupy the forefront position, but then at other times the same child was happy to reside in the background position of the communication process. Thus, the positions children occupied within the communication process were not static, but dynamic and transitory, with children frequently oscillating between the *"overshadowed"* and *"forefront"* extremities of the *"visible-ness"* construct depending on different situational and contextual factors (see Section 6.5.2 and Table 7). These findings challenge the simplistic insistence and uncritical political drive for stronger child

participation in all matters that affect them, in isolation of debates surrounding children's need for support and protection and any resultant potential negative consequences of children's active participation.

This thesis proposes that **both** divisions of the aforementioned dichotomies, such as being *and* becoming, immature *and* mature, incompetent *and* competent, dependent *and* independent, protection *and* participation and the distinct extremities of *"overshadowed" and "forefront,* should be considered in unison (see Appendix 42). The challenge for nurses, and all health professionals, is to determine when it is appropriate to adopt a more protective or a more participatory stance when communicating with children in healthcare. In some way, children's participation must be balanced with children's protection, to provide maximal support, and allow for children's optimal participation. One difficulty with this is that there are no clearly demarcated boundaries between protection and participation, with no one "optimal" extremity for children to occupy (see Section 6.5.2). Instead, the optimal position for children to assume within the communication process is transitory, contextual and based on each child's individual preferences and needs at any given point in time.

To this end, this thesis highlights the need for health professionals to be flexible in their interactions with children and to establish children's individual preferences by continually engaging in an interactive reciprocal process of assessment and reassessment. This will assist with capturing the extent children wish to be involved, or not, in the communication process and their changing needs at different points in time (i.e. the optimal extremity children would like to occupy at any given point in time). To this regard, this thesis recommends that children should not be regarded as a homogenous group operating on generalised assumptions about competencies and abilities of children to participate in the communication process. Although, it is recognised that as this study took place in one ward at one point in time it is difficult to draw assertive conclusions on this. Yet, health professionals' acquaintance with the findings would determine applicability to other settings. Indeed, feedback from presenting at various international

venues affirmed resonance with many aspects of the findings, enhancing the credibility of the results. Therefore, I hope I have provided valuable insights into what hospitalised children value in terms of communication, for nurses, and other health professionals, to reflect upon, appraise and challenge their experiences and practices.

The core construct of *"visible-ness"* and interrelated subject areas (family-centred care, shifting power relations, universal progression versus guided participation, rights negotiation and child as being and/or becoming) enacted in this Child Transitional Communication (CTC) Model (Figure 16 on page 364) suggests that communicating with children is more complex than simply encouraging children's active participation. I acknowledge, however, that although it is commonplace within ethnographic research to include multiple perspectives from all stakeholders within the particular setting (Siraj-Blatchford and Siraj-Blatchford, 2001), these findings are based solely on children's views and my observations and interpretation of children's views. Focusing specifically on the multiple perspectives of children themselves was a conscious decision I made at the outset of this study. I felt it was important to ensure that children's voices remained at the fore, because historically adult proxies (parents, health professionals) have represented the views of children (see Section 4.1). Further research is required to investigate contentions put forth here from other stakeholder (parents and health professionals) perspectives, which would add further valuable dimensions to these findings (see recommendations in Section 8.5.3).

The challenge for health professionals in developing partnerships with children and their families is to acknowledge the consultation rights of children, in addition to recognising the responsibility and rights of parents as children's principal guardians. As previously mentioned, child participants in this study highlighted the importance of being directly communicated with by health professionals but also did not object to the involvement of their parents. This thesis crafts an avenue for more debates within and across various disciplines and discourses. To inform these debates, further research is required to explore parents and health professionals', in addition to children's, perspectives, of the dichotomous conflict between protection and participation, in terms of communicating

with children in hospital and in healthcare, to determine if and how a protection-participation balance can be achieved (see recommendations Section 8.5.3). In light of child participants' perspectives of the nature of the communication on the children's ward, and the propositions put forth here, it was deemed essential to return to re-examine how communication was conceptually defined at the outset of this thesis (see Section 3.3).

### 8.3. Operational Definition of Communication

The findings of this study and the discussions which have taken place within this chapter partially support the operational definition of communication set forth in Section 3.3. Based on initial theoretical explorations, this definition (outlined in Section 3.3) portrayed communication to be a multi-faceted contextual process, within which a message is exchanged and which embodies an intricate set of skills and qualities. Children's stories and my observations from this study support this view. For instance, some important skills, which health professionals used in their interactions with children, and identified by children, were questioning, reassuring and listening (see Sections 6.2.2 and 6.2.3). Health professionals *"humanistic qualities"* (Section 6.4.3), such as being nice, genuine, and funny were also valued by child participants in their engagements with health professionals. There was evidence of a message being exchanged (refer to Sections 6.3.3 and 6.2.3). Finally multiple contextual factors were found to have an important impact on the communication process, as it occurred between children and health professionals at a micro level (see Section 6.4.2), but also at a macro level (see Section 8.2).

However, this definition does not portray the fluidity and individuality of children's communication needs, nor does it illustrate the social inclusiveness or exclusiveness of the phenomenon of communication deemed so important to child participants within this study. Moreover, it fails to take account of the opposing dichotomies (or either/or perspectives) which influence children's positioning within the communication process. Indeed, the findings of this study do not exclusively support the contention that communication is a *"mutually engaging process"*. Rather the findings demonstrated that

the process of communication between health professionals and children was not always a mutually engaged process between two or more people; nor did all children want it to be. In light of this, in the context of communicating with children in hospital, communication is re-defined as:

*Communicating with children in hospital is a dynamic, individualised and contextualised endeavor, which eludes one simple conceptualisation or definition. It is a socially inclusive or exclusive strategy, wedged within a protection-participation dichotomy. To free this dichotomy, communicating with children must be a fluid, flexible, transitory activity, within which* ***both*** *children's participatory and protective needs are attended to. To do this, on-going negotiation between children, their parents and health professionals is required, at each interactive encounter, to determine the degree to which children want to participate, or not, in the communication process.*

Before concluding, it is necessary to explicate the accomplished aim and objectives of this thesis.

### 8.4. Accomplished Aim and Objectives

The aim of this study, to explore the nature of communication for children in one children's ward, had three objectives. Firstly, to explore the process of communication taking place between children and health professionals, in a specialist children's hospital setting. In answer to this objective, the process of communication was conceptualised as a *"visible-ness"* construct. In order to visually operationalise this abstract construct of *"visible-ness"*, it was presented as a continuum with two opposing multi-dimensional extremities, *"overshadowed"* and *"forefront"*, each of which represented the degree to which children were visible, included and their communication needs addressed; or the degree to which children were invisible, excluded and led by the health professional's communication agenda. The findings of this study demonstrated that children were not inertly positioned at one or either of these extremities. Instead children oscillated continually between the *"overshadowed"* and *"forefront"* extremities depending on a number of factors, principally relating to health professionals, parents and children's own communicative behaviours, in addition to the environmental context within which these took place (see Table 7 on page 282). The second objective was to explore the role of the parent/guardian in this communication process. This study revealed that

parents/guardians held a number of diverse roles presented throughout the multi-dimensions of the *"visible-ness"* construct. For instance, parental presence was influential in blocking communication between children and health professionals (see Section 6.2.2), but also parents predominantly acted as intermediary information transmitters and translators between health professionals and their children (see Section 6.3.3).

The third objective was to explore the role of the environment in the communication process. The environment referred to the immediate internal environmental context of the children's ward and broader external social and cultural contexts. The dimension *"competing demands"* (Section 6.4.2) illustrated intrinsic environmental factors, both facilitating (Section 6.4.3) and inhibiting (Section 6.4.2), which influenced the immediate interpersonal process, taking place between children and health professionals on the children's ward. In an attempt to explain why two multi-dimensional extremities *("being overshadowed"* and *"being at the forefront"*) were found to exist, in terms of child participants' experiences of communicative practices on the children's ward, I proposed that there were other extrinsic environmental forces, which potentially explained the dualistic positions/extremities children occupied. These extrinsic environmental forces, which encompassed different dichotomous theoretical perspectives, were expressed within each of the following subject areas, family-centred care, shifting power relations, universal progression versus guided participation, rights negotiation and child as being and/or becoming, as discussed within chapter seven. This thesis presents these subject areas within a Child Transitional Communication (CTC) model and argues that the process of communication on the children's ward is not impervious to but rather susceptible to how children are viewed within society over time. This CTC model challenges an **either/or** approach to communicating with children in health care by recommending the simultaneous consideration of **both** the *"overshadowed"* **and** the *"forefront"* extremities of the *"visible-ness"* continuum, with neither extremity considered more or less effective/important than the other. Prior to the final section of this thesis, which advances recommendations for practice, education, research and policy, I delineate how this thesis has contributed to the advancement of children's nursing.

### 8.4.1. Advancing children's nursing

This thesis plays a crucial role in the advancement of children's nursing, nominally in two key areas. Firstly, the authentic voices of child patients are listened to and heard with their perspectives and experiences reported. Although there is some evidence of nursing research with child patients, this remains at an embryonic stage with the voice of adult proxies (parent/guardian/health professional) often still dominating. Interestingly, the experiences and perspectives of child participants in this study challenge adult propositions for active child participation in all matters that affect them, including health care. In contest of this, child participants highlighted the need to consider participatory discourses not in isolation of, but alongside, or simultaneous with, protective discourses. For instance, while children valued the opportunity to participate in the communication process, they were also appreciative of the presence and support of their parents during this process. This challenges adult (parents and health professionals) practices of working from either a participatory or a protective stance. Secondly, in an era where the overriding emphasis is for nursing practice to be underpinned by a theoretical body of knowledge this thesis is far-reaching in advancing this agenda by exploring multiple theoretical perspectives from a number of different angles; all of which have been and will continue to have an impact on nursing care provided. For instance, this thesis illustrates how the process of communication between children and health professionals is extremely complex and open to many challenges such as beliefs held about children's vulnerability, competency, powerfulness, maturity, dependency, agency and uniqueness; all influential in the social positioning of children within society, and thus within the communication process. Through the development of a new multi-theoretical model of communication, which conceptualises the process of communication at both micro interpersonal and macro socio-contextual level, this thesis creates a platform, and opens many avenues, for future investigation and debate across practice, education, policy and research.

## 8.5. Recommendations

This section proposes a number of recommendations for practice, education, research and policy, respectively.[274]

### 8.5.1. Recommendations for practice

It is recommended that nurses, and all health professionals:

- ❑ Communicate with and include children in the communication process according to their individual preferences by assessing and reassessing continually the extent to which they wish to be involved.

- ❑ Encourage children to express their views by exploring their concerns, worries, and feelings, in an attempt to understand their point of view/perspective.

- ❑ Listen to, acknowledge and demonstrate that children's opinions, concerns, worries, and feelings, are legitimate, as opposed to blocking, dismissing or minimising them.

- ❑ Encourage and offer children an opportunity to ask questions, which will enable children to raise issues of importance to them and allow their communication needs to be addressed.

- ❑ Present sufficient information to children in a clear, easily understood, honest and timely manner, tailored to each child's individual needs, by assessing and re-assessing continually what children want to know, how much they want to know, when they want to receive information, through what medium and from whom they would like to receive this information (e.g. doctor, nurse, and/or parent).

- ❑ Support and work collaboratively with parents to communicate with, and exchange information with children. In this way, parents will not feel abandoned in their role of communication conduit and children will see

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[274] The findings of this study will be disseminated locally to children's wards through information leaflets and posters displayed in clinical areas. Feedback will be provided to child patients in an appropriate format and language, such as a newsletter. To date, I have presented a number of papers at both national and international conferences and one paper has been accepted for publication in a special edition of the Journal of Clinical Nursing. A series of other papers are in the progress. A copy of this thesis will be submitted to the Office of Minister for Children and Youth Affairs.

information exchange as a joint venture between health professionals and their parents.

- ❑ Seek validation of children's understanding by periodically clarifying how children have received and understood information exchanged.

- ❑ Avoid using children's age or previous experience as a universal indicator to determine, whether to explore children's views, the degree to which they should be involved in the communication process, or to determine the amount and type of information to impart to children. Instead, find out different aged children's needs by assessing and reassessing their individual preferences.

- ❑ Create an appropriate atmosphere in which children feel able, comfortable and confident to exert their own agency by asking questions and participating actively in the communication process.

- ❑ Recognise the importance of play and school to children in hospital, however do not presume that busy children are content, do not have concerns and worries, do not want information or are unaware of what is going on around them.

- ❑ Demonstrate your presence, availability and accessibility to children, by frequently checking in with them to see how they are and if they need anything physically and psychologically. Remember *busyness* portrays one has insufficient time available and this discourages children from asking questions and exerting their agency.

- ❑ Avoid merely focusing on documenting children's physical ability to communicate, to include subjective narrative about children's actual communication and information needs, to ensure continuity of care.

**8.5.2.** Recommendations for education

It is recommended that nurse educators, and educators in child health:

- ❑ Include communication education, both practical and theoretical, on all undergraduate and post-graduate curricula for nurses and other health professionals (e.g. medics and allied health professionals) caring for children and their families.

- ❑ Appraise existing teaching and assessment of the phenomenon of communication at undergraduate and post-graduate levels, across disciplines, to examine module content, teaching practices and assessment strategies in

relation to educating children's nurses, and all health professionals, about communicating with children and their families.

- ❑ Explore the incorporation of, and give equal weighting to, real-life practical assessment strategies to assess nurses, and other health professionals, competence in communicating with children and their families.

- ❑ Alongside a specific module on communication education and training, incorporate communication skills education into the teaching of all skills/topics in an attempt to promote holistic care and avoid bifurcation of physical and psychological care.

- ❑ Explore strategies of how to effectively communicate with children and families alongside performing tasks, procedures, examinations and in conjunction with children's busy hospitalised schedule (playing and school).

- ❑ Integrate innovative teaching tools/mediums when teaching nurses and health professionals how to communicate with children of diverse developmental backgrounds, for example, expand the use of play/technologies beyond mere occupational use to therapeutic usage.

- ❑ Incorporate support and coping strategies into communication education modules for nurses and health professionals to enable them to learn and develop strategies for dealing openly with, and not dissociating themselves, from children's emotional needs.

- ❑ Expand communication skills training to incorporate broader contextual issues and critical debates to assist students to examine, recognise and understand relationships between a range of different theoretical perspectives, such as childhood sociology, children's rights, power relations, child psychology, family-centred care, and appropriateness of communication models, in terms of communicating with children and their families.

- ❑ Encourage students to explore how the dichotomies that exist within the aforementioned bodies of knowledge (as outlined in chapter 7 and illustrated on Figure 16) might impact upon the process of communication with children in the context of their family and children's hospital setting.

- ❑ Develop multi-disciplinary communication modules for all health professionals caring for children and their families. This would assist with critical debates across multi-theories, in addition to enhancing consistency among health professionals in their communication with hospitalised children.

- ❑ Provide ongoing in-service education for qualified health professionals, especially in relation to changing political debates and the impact of these in relation to communicating with children.

**8.5.3.** Recommendations for research

It is recommended that childrens nurses, and child health, researchers:

- ❑ Determine from nurses, other health professionals and parents what governs their actions, in terms of communicating with children about their healthcare.

- ❑ Explore parents, nurses and other health professionals' perspectives (positives and negatives) of involving children in the healthcare communication process.

- ❑ Explore nurses, parents and other health professionals, perspectives of their information giving role, in terms of communicating with children, and determine what supports they need to assist them in this role.

- ❑ Use a critical incident technique to explore more specifically with children communicative situations they do and do not want to participate in, or information they do and do not want to receive, and why.

- ❑ Explore with parents, nurses and other health professionals' the strategies they employ and their perspectives of how they cope openly with, or dissociate themselves from children's emotional needs, to determine what supports they need in practice to enable them to explore more specifically and address children's emotional needs.

- ❑ Explore the suitability, advantages, disadvantages and sustainability of employing multimedia technology to enable nurses and other health professionals to effectively engage with children in the context of a busy hospital setting.

- ❑ Explore and document innovative terminology used by health professionals in their communications with children in order to build a substantive knowledge base/dictionary to guide all healthcare practitioners in their interactions with child patients.

- ❑ Investigate and compare children's, parents and health professionals' perspectives about what constitutes the optimal positioning of children in the communication process in different situations/circumstances and how this can be achieved.

- Explore the dichotomous conflict of protection *versus* participation with parents, nurses, other health professionals and children to see how a balance can be achieved, and determine how adults can work with children through guided participation to develop their competency to participate in the communication process at a level they desire to be optimal.

- Investigate relationships between the views and attitudes of parents, nurses and other health professionals towards children and childhood and their communicative actions/behaviours and degree of involvement of children in the communication process.

- Compare the opinions of healthy and sick children regarding what constitutes optimal/effective communication with different adults (parents, teachers, nurses and other health professionals) in different situations/settings in everyday life, and how this differs, or not, from communication with children in healthcare.

- Collect large scale quantitative data on children's healthcare communication needs to determine more specifically differences, or not, between variables such as age, gender, diagnosis and previous healthcare experience.

- Explore the communication needs of younger children (< 6 years), children from different cultural backgrounds, children with disabilities and children attending different healthcare settings (e.g. non-specialist children's hospitals).

**8.5.4.** Recommendations for policy

It is recommended that policy-makers concerned with children's healthcare:

- Develop communication guidelines for the care of children in hospital, which should incorporate advice for nurses, and all health professionals on been open and flexible in their communications with children, and their families, according to their individual preferences.

- In conjunction with the above guidelines, hospitals, and wards/units caring for children, should develop philosophies and strategies for communicating with children and their families in healthcare.

- Engage in critical debates on the protection-participation dichotomy to try to determine how optimal participation of children in matters that affect them can be achieved alongside ensuring children's protection.

- Continue to commission research exploring children's perspectives on matters that affect them, especially in health care and more specifically in nursing

wherein lies a dearth of research which maximises the voices of children and young people.

## 8.6. Conclusion

This thesis is original in its contribution by explicating a multi-theoretical perspective on the scant body of nursing knowledge about communicating with children in hospital. In doing this, it attempts to bring together the different dimensions of communication practices taking place on the children's ward, as described by child patients, along with my observations and conceptualisation of why what is happening in terms of communication between children and health professionals on the children's ward is. This is extremely important if we are to advance the mission of building a rich theoretical body of knowledge, in relation to communication with children, and their families, in healthcare, because as previously highlighted this is an area that is much under theorised.

While some of the findings of this study are similar to other Irish studies (e.g. Coyne et al, 2006; Kilkelly and Donnelly, 2006), and without negating the valuable contribution of these studies, this thesis builds upon these descriptive studies by offering exclusive theoretical perspectives and thus adds to the limited, but developing, body of evidence about communicating with children in healthcare, and more specifically nursing practice. While recognising that the interpretation put forth here is but one, upon reading this thesis other scholars might generate additional different interpretations, a view consistent with the epistemological underpinning of this thesis, that of multiple social constructions (see Section 4.2.2). I advocate for further research in other settings to determine similar or different concepts, which may modify the interpretations put forth here. This will enable us to progress in building a body of knowledge surrounding children's communication needs, and how we can best address these, in healthcare.

Finally, the most frequent apprehension raised is whether interpretation is truly evident in the empirical data or arises from the researchers subjective assumptions (Leininger, 1994; Koch, 1994). The outcome of data analysis is to create something new, which is different,

yet remains faithful to the original data (Sandelowski, 1995),[275] therefore combining both *etic* and *emic* perspectives. Within this thesis, I believe, I have remained close to the child participants' perspectives, but also have created something new, in terms of offering a multi-theoretical perspective in an attempt to explain the different communicative practices taking place within the research setting of the study (an inpatient children's ward in a specialist children's hospital). I was inherently part of this research setting and am inherently embedded within this thesis, alongside child participants. As Smith (1990) highlights, in constructivism any insinuation of a subject-object dualism is abandoned in favour of an interaction between researcher and researched.

> "Who is, after all, objective in this world? No human being can be completely objective. We cannot rid ourselves of our experiences. We can however, become aware of our experiences, our opinions, and our values. As a result, bias is a human condition, a danger for both insider and outsider researcher" (Zaman, 2008:152).

*My assumptions and values are that I am passionate about the care of children in hospital. The aim of this study was to bring child's voice to the foreground. At the outset of this study, I was aware of the increasing drive, for this to happen. This inevitably had an impact on how I viewed children and their positioning within the process of communication and in society in general. However, I was not sure what position children did assume in healthcare. I knew that children's voices were not necessarily at the foreground, if ever. From my own training, as a children's nurse, I was aware of the lack of focus on communication strategies with/for children. Thus, communicating with children was something I found challenging, especially moving from an adult healthcare setting and having no prior experience of working with children (yet it was always children's nursing that I wanted to pursue). I trained in an era when the overriding focus was on parents and family-centred care (but I had never explored literature extensively surrounding this until undertaking this thesis). Once qualified, I worked in the area of neonates and infants. Thus, perhaps it was surprising that I choose to do this research with older children. However, maybe this helped my insider-outsider role. I was essentially an insider to the hospital setting, being a nurse, but I was also an outsider because I had worked minimally with children older than infancy since qualifying as a children's nurse. I think this perspective, of believing that children's voices were not necessarily always heard, led me to look beyond instances of when children were not communicated with or when their voice was not heard (for often these*

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[275] Harden et al (2000:7) highlighted that "if academic research is to produce anything more than lay understandings it must include access to concepts, theories and scholarly knowledge unavailable to most research subjects".

*instances stood out from the data for me clearly to other instances). However, I had not thought about the fact that children might not want to be communicated with or want inclusion (as shown in chapter six). Thus, I started to re-evaluate the concept of participation or inclusion. There could have been the risk that I would have overlooked this with the overwhelming drive for active child participation in all matters that affect them. I also assumed, as is often argued within the literature, and with most things, that age matters. I spent time looking closely across the data sets but I could not be conclusive about this issue. Although I was aware of the impact of the environment on communication there were other contextual issues that I had not considered in-depthly before. I was aware of the importance of play for children in hospital, yet I had not examined this in relation to communication before. Thus, despite my training, as a children's nurse, undertaking fieldwork from a different perspective allowed me to look and contemplate on key issues about communication within the children's ward from different angles, based on what children were saying and what I was observing. I believe that this study offers new perspectives and contributes original insight into communication practices with children in a hospital setting. I have examined the findings across a number of different theoretical perspectives about how children are viewed, which must be considered, not in isolation, but in conjunction with communication theories, if we are to advance research, education, practice and policy.*

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# APPENDIX 1

# TEN ARTICLES OF THE EACH CHARTER FOR CHILDREN IN HOSPITAL

**Ten Articles of the EACH Charter for Children in Hospital**

| | |
|---|---|
| Article 1 | Admit children to hospital only if care cannot be given at home or on a day basis |
| Article 2 | Children have the right to have their parents/parent substitute with them at all times |
| Article 3 | Availability of accommodation for parents with no extra cost<br>Inform parents about ward routine and encourage their participation in child's care |
| Article 4 | Inform children and parents in a manner appropriate to age and understanding<br>Instigate steps to mitigate physical or emotional stress |
| Article 5 | Involve children and parents in all decisions involving their health care<br>Protect children form unnecessary medical treatment and investigation |
| Article 6 | Care for children with other children with similar developmental needs<br>Do not restrict age for visitors to children in hospital |
| Article 7 | Provide children with full opportunity for play, recreation and education suited to their age and condition in an environment designed, furnished, staffed and equipped to meet their needs |
| Article 8 | Staff caring for children should be those who are trained and skilled to respond to the physical, emotional and developmental needs of children and families |
| Article 9 | Ensure continuity of care |
| Article 10 | Treat children with tact and understanding and respect their privacy at all times |

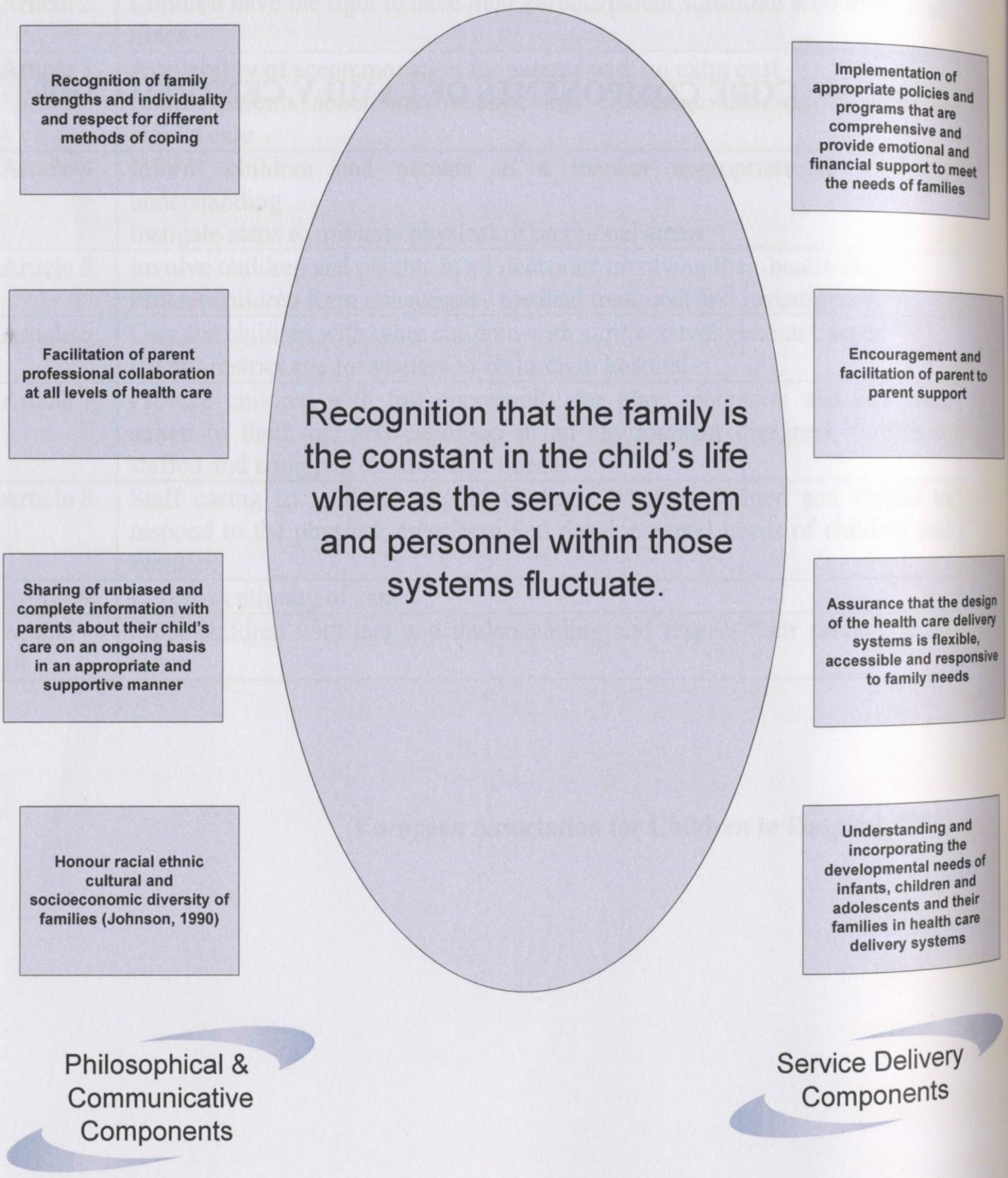
**(European Association for Children in Hospital, 2002)**

# APPENDIX 2

# CORE COMPONENTS OF FAMILY CENTRED CARE

# Major components of family-centered care

Aspects of diagram adopted from Brown, W., Pearl, L. F., Carrasco, N. (1991) Evolving models of family-centered services in neonatal intensive care. Child Health Care. 20 (1): 50-55.
Elements of Family Centered Care outlined are as those described by ACCH (Shelton, Jeppson and Johnson, 1987)



# APPENDIX 3

# COMMUNICATION MODELS AND FRAMEWORKS

| AUTHOR | MODEL/ FRAMEWORK | WHAT INFORMED THE DEVELOPMENT OF THE MODEL/ FRAMEWORK? | ELEMENTS OF MODEL/ FRAMEWORK |
|---|---|---|---|
| Szasz and Hollender (1956)<br><br>USA | Basic models of doctor-patient relationship | Stated their approach was influenced by psychologic (psychoanalytic), sociologic, and philosophic considerations. | **Three paradigms of doctor-adult patient relationship**<br>*Activity-Passivity*: The patient assumes a passive role and the doctor an active role doing something to the patient. The physician is in total control (suited for emergency situations) (similar to a parent-infant relationship)<br>*Guidance-Cooperation*: Doctor is expert, tells the patient what to do, patient obeys the medical regimen outlined by the physician because he/she does not possess the knowledge to dispute (suited for acute cases) (similar to a parent-child (adolescent) relationship)<br>*Mutual Participation*: Degree of equity between doctor and patient, doctor adopts an assistive role helping the patient help him/herself (suited for patients with chronic illnesses) (similar to a adult-adult relationship) |
| Berlin and Fowkes (1983)<br><br>California | A teaching framework for cross-cultural health care | Proposed this model as a teaching framework to increase awareness and cultural sensitivity among health professionals. Stated model developed by building on methods of elicitation suggested in the literature. | **Proposed LEARN Model**<br>*Listen* with sympathy and understanding to the patient's perception of the problem<br>*Explain* your perceptions of the problem<br>*Acknowledge* and discuss the differences and similarities<br>*Recommend* treatment<br>*Negotiate* treatment |
| Thorne and Robinson | Relationships between healthcare | Family perspectives of healthcare relationships in | **Three evolving periods** families progressed in their relationships with health professionals |

| | | | |
|---|---|---|---|
| (1988)<br><br>Canada | providers and healthcare recipients | chronic illness - secondary analysis of data from two studies: family members of adults with cancer and parents of chronically ill children | *Naïve trusting*: families trusted health professionals to act in best interests of sick family member, but soon discovered this trust was naïve, often discrepancies existed between what families and health professionals considered best interests.<br>*Disenchantment:* families dissatisfied and frustrated with care, difficulty acquiring information and faced dilemma of deciding whether to intervene or not.<br>*Guarded alliance*: reconstructing trust and cooperative caring, families actively sought information, stated their perspective and expectations more clearly and promoted negotiation of mutually satisfying care. |
| Casey (1988)<br><br>UK | Partnership with child and family<br><br>Paediatric nursing model | Descriptive model<br>No information given on what informed the model development (see Lee (1998) for critique) | **Four main concepts**<br>*Person*: child and family, child unique entity, growing and developing human being who has rights in law (moves from state of dependence to independence)<br>*Health*: optimum physical and mental well-being<br>*Environment*: safe and suitable in order for child to flourish<br>*Nursing*: paediatric nurse complements parental care, supports and teaches<br>The process of nursing is carried out in *partnership* with child and his family *(does not state how to operate this partnership in practice)* |
| Morse et al (1992; 2006)<br><br>Canada | Nurse Adult Patient Emotional Engagement | Autobiographical and biographical accounts of caregiver patient interactions from lay literature | **Four types of communication patterns**<br>(1) Patient-focused: First level (reflexive): *Engaged* (connected response)<br>(2) Self-focused: First level (reflexive): *Anti-engaged* (reflected response)<br>(3) Patient-focused: Second level |

| | | | |
|---|---|---|---|
| | | | (learned): *Pseudo-engaged* (professional response)<br>(4) Self-focused: Second level (learned): *A-engaged* (detached response) |
| Fosbinder (1994)<br><br>USA | An emerging theory of interpersonal competence | Adult patient's views of what happens when nurses are caring for them: an ethnographic study of interviews and observations with 40 adult-patients and 12 nurses.<br>Nurse's interpersonal competence identified as primary concern | **Four interpersonal processes**<br>(1) *Translating:* information giving, explaining and instructing<br>(2) *Getting to know you:* being friendly, using humour and personal sharing<br>(3) *Establishing trust:* confidence in nurses professional competence and demeanour<br>(4) *Going the extra mile*: being a friend and doing more than is required |
| Ahmann (1994)<br><br>USA | Adapted the LEARN model for use within the philosophy of FCC | Adopted from Berlin and Fowkes (1983) LEARN model (see above) | **Mnemonic LEARN**<br>*Listen* with sympathy and understanding to the family's perception of the problem<br>*Explain* your perception of the problem<br>*Acknowledge* and discuss the similarities and differences<br>*Recommend* treatment<br>*Negotiate* treatment |
| Ahmann (1994)<br><br>USA | Adapted the Nursing Mutual Participation Model of Care (NMPMC) for use within the philosophy of FCC | NMPMC emerged for employment within medical interactions in adult settings for use with chronically ill adults (Szasz and Hollender, 1956) and evolved into nursing and pediatric care (Curley, 1988) (USA) | **Four Steps**<br>**Step 1:** Use of open-ended questions to establish a caring atmosphere, e.g. how is it going for you?<br>**Step 2:** Use of direct questions to ascertain parental goals and expectations, e.g. how did you hope I could help you (parent your child) today?<br>**Step 3:** Assessment of parent's perception of child's illness through questions such as, how does your child look to you today? How do you think your child is doing?<br>**Step 4:** Elicit parents' suggestions/preferences and invite parents to participate in care, e.g. do you have any questions or suggestions concerning your child's |

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| | | | care? Is there anything you personally wish to do for or with your child? |
| Casey (1995)<br><br>UK | Involvement in Care: Nursing Approaches<br><br>Practical implications of the effect that communication and nursing style had on parent involvement in their child's care | Data were collected, about children in hospital, their families, what care they required and the families involvement in that care, through structured interviews with nursing staff and from secondary sources such as medical and nursing records. | **Four Approaches**<br>(1) Communicating/nurse centred: *permission* nurses authoritative and controlling in communication with families, nurses did assess parental wishes, however allowed parent involvement only on their terms<br>(2) Non-communicating/nurse-centred: *exclusion* nurses excluded parents<br>(3) Non-communicating/person-centred: *assumption:* nurses made subjective judgements/assumptions of family needs/wishes based on their subjective opinions, with no record or mention of systematic assessment<br>(4) Communicating/person-centred: *negotiation:* nurses did communicate and share expertise/knowledge and listened to families |
| Smith (1995)<br><br>UK | Nottingham Model<br><br>Child and family focused care | Development of model resulted from reflection upon practice and a vision for an ideal, led by practitioners and educationalists involved, influenced by some feedback from parents (lack of negotiated care) | **Two main concepts**<br>(1) Care centred on the child and family<br>(2) Negotiated care<br>This facilitates a caring approach and the achievement of equal partnership between professionals and child/parents and family<br>Acknowledged the child should be involved in assessing and planning needs; for this to happen the nurse must possess excellent communication/interpersonal skills. |
| Morse, Havens and Wilson (1997)<br><br>Canada | Comforting Interaction – Relationship Model<br><br>Argued separate literature on nurse-patient interaction and | Proposed a model that accounts for all nurse-patient interactions and relationships<br>Conceptualisation derived from an analysis of research literature describing | **Three Components**<br>*Nursing actions*: 3 interrelated levels - comfort strategies, styles of care, and patterns of relating<br>*Patient actions*: signals of discomfort, indices of distress, patterns of relating<br>*Evolving relationship*: with each interaction the evolving relationship |

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| | relationships fragments a unified process | nurse-patient interactions and relationships | develops<br>It is through this interaction of nursing actions and patient actions that the nurse-patient relationship is negotiated |
| Mead and Bower (2000)<br><br>UK | Patient-centredness | Reviewed conceptual and empirical literature (quantitative work) to take stock of existing literature in order to develop a model of aspects of doctor-patient relationship encompassed by concept patient-centredness | **Five Conceptual Dimensions**<br>(1) *Bio-psycho-social perspective*: understand patient illnesses within a broad bio-psycho-social framework<br>(2) *Patient-as-person*: understand patient subjective experience of illness<br>(3) *Sharing power and responsibility*: shift doctor-patient relations from cooperation-guidance to mutual participation where power and responsibility are shared<br>(4) *Therapeutic alliance*: greater priority to personal relationships between doctor and patient – attitudes of empathy, congruence and unconditional positive regard<br>(5) *Doctor-as-person*: personal qualities of doctor<br>A large number of **variables** which potentially influence a doctors propensity to be patient-centred;<br>*Shapers*<br>*Doctor factors*<br>*Patient factors*<br>*Professional context influences*<br>*Consultation level influences* |
| Sydnor-Greenberg and Dokken (2001)<br><br>Origin not stated | Thoughts on the child's perspective: communication in healthcare | Conversations with "several" children and adolescents aged 4 to 17 years about communicating with healthcare professionals.<br>Children had a history of common childhood conditions, as well as children with both chronic and acute conditions. | **Mnemonic CLEAR**<br>Communication framework to assist with understanding what children would like in their interactions with health professionals<br>*Context*: whole person, life outside illness<br>*Listening*: valued when listened to<br>*Empowerment*: empowered when communicated with directly and informed<br>*Advice*: health promotion<br>*Reassurance*: about their health was important |

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| Alsop-Shields (2002)<br><br>Cross-cultural | Parent-staff interaction model of pediatric care<br><br>A philosophical model – a way of seeing family and interacting with them | Model developed from findings of a large multinational study that investigated the way children are cared for in hospitals in both developed (Australia and Britain) and developing countries (Indonesia and Thailand)<br>Subjects were parents of hospitalised children, nurses, doctors and allied health staff. | **Parent-staff interaction model**<br>2 main components – *parent presence* and *communication between staff and parents*<br>Core element in model is parent and child as a *single unified individual unit*<br>They are placed in *hospital (environment)* and surrounded by staff – a separate unit<br>*Communication* is the linking factor between the parent-child single entity and the staff unit<br>*Health (or depletion of it)* is inherent within model<br>*Action* = communication between parent and staff |
| Figueroa-Altman et al (2005)<br><br>USA | KIDS CARE Improving partnerships with children and families | Idea for KIDS CARE came about because of discussions between a bedside nurse, a CNS (Mental Health) and a mother of a chronically ill child, following several upsetting encounters with an increasingly hostile father.<br><br>KIDS CARE became a training/orientation programme for newly qualified nurses | **Mnemonic KIDSCARE**<br>*Knock*: before entering families temporary personal territory to alert occupants and prevent awkward situation<br>*Introduce*: state your name, role, length of shift to orient families/patient to staff<br>*Determine*: who is at bedside and how patient/family like to be addressed<br>*Safety*: demonstrate to family members strict adherence to safety standards and explain reasons for them<br>*Clean hands*: wash hands in front of patient and family members and put on fresh gloves pre procedures<br>*Advocate*: listen to family concerns, use open questions to elicit family preferences<br>*Respond*: let families know your availability and accessibility<br>*Explain*: who you are and what you are going to do, allow time for questions, involve family |

# APPENDIX 4

## DEFINITIONS OF ETHNOGRAPHY FROM VARIOUS PERSPECTIVES

| Defining Ethnography | Author |
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| Definition of the term ethnography has been subject to controversy. For some it refers to a philosophical paradigm to which one makes a total commitment for others it designates a method that one uses as and when appropriate. And, of course, there are positions between these extremes. | Sociology Atkinson and Hammersley, 1994:248. |
| 'Ethnography' plays a complex and shifting role in the dynamic tapestry that the social sciences have become in the 21st century. This term is by no means unusual in **lacking a single, standard meaning**. We can outline a core definition, while recognising that this does not capture all of its meaning in all contexts.<br>According to the naturalist account, the value of ethnography as a social research method is founded upon the existence of such variations in cultural patterns across and within societies, and their significance for **understanding social processes.** | Sociology Hammersley and Atkinson, 2007: 2 Hammersley and Atkinson, 2007: 9 |
| Ethnography is the **work of describing a culture**. The central aim of ethnography is to understand another way of life from the **native point of view**. | Anthropology Spradley, 1980: 3; viii |
| The social research style that emphasises encountering alien worlds and making sense of them is *ethnography*, or "folk description". | Anthropology Agar, 1986: 12 |
| Ethnography is a **collaborative participatory methodology** The representation you build is neither 'theirs' nor is it 'yours'. | Anthropology Agar, 1996: 36 |
| Ethnography is an ambiguous term, representing both a **process** and a **product**. The product is usually a book. The book almost always focuses on some **social group**, though it may be guided by any number of theories and methods. There will be a dash of history, something about the various environments – physical, biological, and social – and some detail on the things the group does and the beliefs they hold. | Agar, 1996: 53 |
| Ethnography is the **art and science of describing a group or culture**. The description may be of a small tribal group in an exotic land or a classroom in middle-class suburbia. | Anthropology Fetterman, 1998: 1 |
| More anthropologically oriented writers make distinction between ethnography as ***process*** and ethnography as ***product***.<br>"Ethno" refers to people, and "graph" to a picture, then the challenge of **presenting a picture of a group of people** seems to provide direction enough for many a researcher.<br>For the anthropologically oriented researcher, ethnography has always been associated with and intended for **studying culture.** | Anthropology Wolcott, 1999: 41; 62; 67 |
| Ethnographic research involves the use of a **variety of techniques** for collecting data on **human beliefs, values, and practices**. | Anthropology Hume and Mulcock, 2004: xi |
| Ethnography is a way of collecting, describing, and analysing the ways in which **human** beings categorize the **meaning of their world.** In other words, ethnography attempts to learn what knowledge people use to | Nurse Anthropologist Aamodt, 1991: 41 |

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| interpret experience and mold their behaviour within the **context** of their **culturally constituted environment.** | |
| The essential purpose of *ethnography*, which literally means "a portrait of a people", is to understand a **cultural group's** way of life from the **"native's" point of view**. Ethnography is used to describe and explain the regularities and variations of **social behaviour**. | Nurse Anthropologist Lipson, 1994: 339 |
| An ethnography is always informed by a concept of **culture**.<br>An ethnography focuses on a **group of people** who have **something in common.** | Transcultural Nurse Boyle, 1994: 160; 161 |
| Ethnography is a research process of **learning about** people by **learning from** them.<br>The researcher's observations, feelings, and understandings gleaned from participation observations, interviewing, and additional sources, are documented in fieldnotes, which are then analysed to reveal answers to the questions asked by the research project. The result of this written description and analysis is called ethnography; thus, ethnography is both a **process and a product**.<br>This blend of "knowing" from both an insider's perspective and an outsider's analysis allows deep and rich insights about the behaviours and beliefs of individuals as they navigate their social world. | Nursing Roper and Shapira, 2000: 1-2 |
| It consists of the **study of social life, social world**, or other aspects of the **culture of a particular group or social setting**. Ethnography constitutes both **method** (mainly involving fieldwork) and **perspective**. In using the term ***ethnographic perspective***, the aim would be to convey, in a relatively shorthand form, a sense of acceptance of a **number of assumptions** about research activity and the derivation of knowledge. | Nursing Adaptation Johnson, 1997: 8 |
| At its simplest level, 'ethnography' can refer **to a way of collecting data** (a set of research methods); the **principles that guide the production of data** (a methodology); and/or a **product** (the written account of a particular ethnographic project). | Nurse Anthropologist Savage, 2006: 384 |
| Ethnography is both a **product** – the book which tells a story about a group of people – and a **process** – the method of inquiry which leads to the production of the book.<br>Ethnography also is an **investigative process** which social scientists **employ in different ways to study human behaviour,** depending upon their discipline. | Education LeCompte and Preissle, 1993: 1-2 |

# APPENDIX 5

# KEY CHARACTERISTICS OF ETHNOGRAPHY

**Key characteristics of Ethnography**

- Exploring: its about discovery
- Relies on collection of data in natural environment
- Value placed on context: cannot study people independently of their environment
- Observing what people do: do not rely totally on what people say, but also see it, visualise it, create a picture of it through firsthand experience of it
- Searching for context: does not de-contextualised like an artificially structured interview
- Phenomena cannot be analysed divorced from social and cultural context
- Not just about immediate social and cultural context but also broader socio-economic and political context
- Emphasising the native's perspective
- Multiple perspectives including researcher and researched (*emic* and *etic*)
- Intimate relationship between researcher and researched
- Using a variety of different methods: multi-modes of data collection
- Working with unstructured data
- No variables purposively manipulated
- Becoming progressively focused: start with broad descriptive inferences
- Being reflexive: conscious thought: researcher as prime instrument of data collection
- Interpreting meanings of human action
- Analytic induction
- Being guided by and generating theory
- Culture, holism, naturalism, flexibility, creativity

# APPENDIX 6

# PILOT WORK SUMMARY

Selection of Pilot Cases

The pilot stage of this study involved one child (aged 7 years) and one young person (aged 12 years) who both suffered from a chronic illness. They were chosen purposefully through liaison with a Clinical Nurse Specialist. The reasons for selecting these two pilot cases were; they were admitted to the research hospital site at the time of undertaking the pilot work and it was anticipated that they would be in-patients for at least two weeks. This was deemed important because it would allow me to build rapport and develop a relationship with the children. Furthermore, both cases were well, admitted for a course of intravenous antibiotics and had extensive experience of the hospital setting with numerous previous inpatient admissions. Thus, it was felt they would have substantial knowledge of the hospital setting and they would be at ease talking about their experience.

Profile of Pilot Cases

*Case one*

My first case was a 7-year old boy John (pseudonym) with Cystic Fibrosis. John and his mum had attended the day ward for a routine review, following which it was decided to admit John. John had presented with increased coughing for five days previously, increased sputum, shortness of breath, a temperature, reduced pulmonary function tests and a reduced appetite. A viral infection was diagnosed and John was admitted for a 2-week course of intravenous antibiotics. I met John seven days following his admission. In addition to receiving intravenous antibiotics every few hours, John's care involved blood tests, nebulisers, physiotherapy, X-rays, pulmonary function tests and PEG tube feeding. John had a port-a-cath for the administration of his intravenous antibiotics. John mum came every day at various times and sometimes stayed overnight especially if John was upset or if he was due for blood testing in the morning. Since John was 7 months old he had approximately 28 admissions as an inpatient to the hospital, in addition to, outpatient visits and day stays. John was nursed in a 6-bedded room of a busy medical ward.

*Case two*

A 12-year old girl Ann (pseudonym) was my second pilot case. Ann also had Cystic Fibrosis. Ann was diagnosed when she was two and a half years old and since then has been an inpatient in hospital approximately once a year with a record of 11 previous hospital admissions. This admission Ann presented with haemoptysis and was admitted to a single room for isolation purposes. Ann's care involved blood tests, nebulisers, X-rays, sputum specimens, intravenous antibiotics and physiotherapy. Ann's intravenous antibiotics were administered through peripheral cannulas which needed re-siting on a daily basis. Ann was nursed in strict isolation. This meant she could not attend the playroom. Ann's cousin stayed with her throughout her hospital stay. Her mother and younger brother visited daily and Ann was also allowed 'out' for hours in between getting her intravenous antibiotics. As she lived nearby this enabled her to go home or go to the shops and meet her friends.

Nature of Pilot Inquiry

When I first entered the field nothing was focused. I did not have a research question as such; I just wanted to learn about children and young peoples experiences of hospitalisation. The main reason for my unfocused approach was the difficulty I had with predetermining topics that I as an adult felt were worthy of investigation. These may not mirror children and young peoples concerns. I wanted children and young people to decide what was important to them. At the beginning I asked myself what was it I am supposed to be doing and observing. I began by recording as much as I could of what was going on and things that the child and young person said or did. I followed John throughout his admission spending 33 hours in total with him. During this time I chatted to him, played with him, sat with him, observed him, went to physiotherapy, X-ray, pulmonary function tests and the playroom with him. I also spent time chatting to his mum and met his family. John was given the opportunity of choosing what activities he would like to take part in. He was happy for me to spend time following him throughout his hospitalisation. Substantial field notes were recorded. He was intrigued by the disposable camera and enjoyed this activity. One formal interview using a minidisk player was attempted. John's mum was present for this. John was not really interested in

drawing or writing. Ann was also given the choice of activities. She choose to keep a diary, drew one picture of the physical hospital structure chatted informally and took some photographs. Ann did not want me to spent substantial amount of time with her so I visited for short periods daily. She did not want to use the minidisk player. I met Ann five days after her admission and spent a total of 3 hours with her (this illustrates differences in child participant preferences).

Report from Pilot Cases

Firstly, as I progressed through the pilot stage it became distinctively clear that children's experience of hospitalisation was a very extensive area for exploration with a multitude of possible lines of inquiry. This initial period of pilot work was influential in focusing the study. One of the biggest lessons gained from the pilot work was the necessity to refine the study and formulate more specific research questions. Secondly, my presence with children as *individual cases* emerged as an influential factor in their hospital experience. This is illustrated here by an extract from my field notes; *as we began playing, he (John) said this (game) is good, stating he was bored before I arrived* (Pilot Case One Field Notes pg 9). Furthermore, upon reflection I had noted that by focusing on the children as individual cases I neglected to take into account the context of the children's setting. Thirdly, in the initial recruitment stages some concerns emerged. It had been decided at the outset that the process of recruiting children would be dependent on the Clinical Nurse Specialist's (e.g. Cystic fibrosis, Diabetic, Renal). I met individually with each CNS and maintained contact via email as reminders for my sample recruitment. Two issues emerged. They often forgot to contact me about potential child cases only remembering when they saw me in around the hospital. This is understandable owing to their workload and as Stalker et al (2004) points out recruiting children for someone else's research study is unlikely to be their priority. The second issue was the criteria the CNS's sometimes used to select potential participants and the reasons for exclusion. Wagstaff and Gould (1998) refer to this as informed consent related bias. This is where participants thought to be less agreeable are not approached for their consent to take part. Additionally, some parents expressed concern about the amount of actual time I would be spending with their child. They announced that their child's hospitalisation was an

emotional and tearful time for them and they would be uncomfortable with my presence. Finally, I was also conscious of my presence on the ward spending time with some selected children and wondered did other children feel neglected.

In relation to field procedures, finding an appropriate time amid all hospital routines to actually talk to children about their experience proved difficult. Despite the fact that I spent a considerable amount of time on the children's ward it was very busy with plenty of activity and things happening all around. Furthermore finding an appropriate venue, space and privacy proved even more difficult. One organised conversation was attempted in the treatment room with John in the evening time. John had decided to hold it in the treatment room and had negotiated this with the ward staff himself. Mum also attended. This provided an opportunity to use the minidisk player. John was very interested in the minidisk player and microphone and controlled it throughout following some demonstration and rehearsal. No pre-structured questions were set although some incomplete sentence cards were prepared. However it was felt that doing this organised interview in this unnatural setting was not ideal. While John used some of the incomplete sentence cards, I felt he was searching for right answer. Furthermore, mum helped John with his answers. The photographs worked well, however I did encounter some minor issues. In using the first disposable camera John had not used the flash. Another camera went missing. In Ann's case she was discharged home before all the photos had been taken and therefore I was unable to develop them and discuss them with her. Neither Ann nor John were interested in drawing any pictures. Ann kept a diary which worked well, however did require motivation to keep recording daily and she needed guidance about what kind of things to write about. The observations went well but produced a plethora of field notes highlighting the need for some predetermined structure.

Changes made

In lieu of the above emerging concerns the following changes were made. Firstly, on examination of the field notes, reflection on my field work experience and a revisit to the literature the study was more focused and the following research question emerged: What is the nature of communication between children and health professionals in a children's

hospital setting? Next, it is proposed to redefine the case as a ward that is one selected ward within a specialist children's hospital. The children within this ward would be invited to take part in the study in order to explore and describe their experiences of communication within the context of children's hospital environment. Paying cognisance to the organisational context would be vital in answering the aforementioned emerging research question. Using the *ward* as a case would address this issue. Redefining a ward as the case would also help overcome the recruitment and selection problems. All children admitted to the selected ward case within a certain time frame would be invited to take part. Rather than spending considerable time with any one child I would now be spending time on a ward among a number of children, this would address parents concerns.

# APPENDIX 7

# ETHICAL APPROVAL CORRESPONDENCE

# Letter Granting Ethical Approval from the School of Nursing and Midwifery Research Ethics Committee

**The University of Dublin, Trinity College**
Faculty of Health Sciences
**School of Nursing & Midwifery Studies**
Trinity Centre for Health Sciences, St. James's Hospital, James's Street, Dublin 8.
Tel: + 353 1 6082692 Fax: + 353 1 4732984/6083001 http://www.tcd.ie/Nursing_Midwifery/

Veronica Lambert
1. Ormonde Terrace
Blackhorse Avenue
Dublin 7

**Re: Application to Research Ethics Committee 19/04**

Dear Veronica

Further to your recent application to the School of Nursing and Midwifery Studies Research Ethics Advisory Committee I am writing to inform you that the committee considered your application at their meeting on February 19th and permission to *proceed to the Faculty of Health Sciences Ethics Committee has been granted subject to you addressing the following points:*

1. Please proof-read child's information sheet to ensure correct meaning. Please change word 'partake' to 'take part' in.
2. Please ensure that you have included that the interviews will be taped both in the body of the application and on the information sheets.
3. Please provide greater rationale for different data collection methods to be employed.

Please inform camccabe@tcd.ie by e-mail by March 1st at 16.30hrs or earlier how each point has been/will be addressed. Catherine will then respond to you by e-mail. If permission is granted to proceed by Catherine, please note that you need to have your application to Faculty in by March 8th. Please note that Faculty want two signed hard copies and one by e-mail. Please send to fmcnamar@tcd.ie.

A copy of this letter has been forwarded to your supervisor

Yours sincerely,

Dr. Michèle Glacken
**Chairperson of Research Ethics Committee**
**School of Nursing and Midwifery Studies**

## Letter Granting Ethical Approval from the Faculty of Health Sciences, Trinity College

THE UNIVERSITY OF DUBLIN
TRINITY COLLEGE
FACULTY OF HEALTH SCIENCES

Dean: Professor Diarmuid Shanley
Faculty Secretary: Ms Fedelma McNamara

Trinity College, Dublin 2, Ireland
Telephone: 353-1-608 1476
Fax: 353-1-671 3956
Email:dshanley@tcd.ie
fmcnamar@tcd.ie

Monday 19th April 2004

Ms Veronica Lambert
1 Ormonde Terrace
Black horse Ave
Dublin 7

Re: Children and young people's experiences of hospitalisation

Dear Ms Lambert

Further to your revised application, we are pleased in inform you that the above project has been approved without further audit.

Yours sincerely

pp

Professor Noel Claffey
Chairperson
Faculty of Health Sciences Ethics Committee

Ref: NG/FMeN – Ethics Approval – Veronica Lambert

**Initial response from the Children's Hospital Ethics Committee**

**Note:** Letter heading, footer and signature have been chopped to maintain confidentiality.

Ms. Veronica Lambert,
1 Ormonde Terrace,
Blackhorse Avenue,
Dublin 7.

22nd April 2004

**Re: 04 009: Children and young people's experience of hospitalisation**

Dear Ms. Lambert,

The Ethics Committee met on 20th April and the above proposal was discussed. The committee was very impressed with the comprehensiveness of the documentation.

This study can proceed when you obtain consent from the clinicians / consultants to spend time with their patients. Rather than approach each consultant individually, it was suggested that you might contact [redacted] Chair of the Medical Board, with a view to obtaining blanket consent.

I look forward to hearing from you.

Yours sincerely,

**Letter Granting Blanket Consent from the Medical Board of the Children's Hospital**

**Note:** Letter heading, footer and signature have been chopped to maintain confidentiality.

28th May 2004.

Ms. Veronica Lambert,
MSc Research Student,
School of Nursing & Midwifery,
University of Dublin,
Trinity College.

Re: **Consent to spend time with patients for Research Study entitled "Children and Young Peoples' Views of their Hospital Stay"**

Dear Ms. Lambert,

Many thanks for your recent letter to the Medical Board of the Children's University Hospital requesting blanket consent from consultants working within the hospital to allow you to spend time with their patients in order to carry out the above research study. At the recent meeting of the Medical Board the consultants supported your request subject to the following conditions:

1. that corroboration of Ethics Committee approval is submitted to the Medical Board
2. that close liaison with the Ward Sisters takes place during the period of time when children are been assessed.

Best wishes with your research project.

Yours sincerely,

**Letter Granting Ethical Approval from the Children's Hospital**

**Note:** Letter heading, footer and signature have been chopped to maintain confidentiality.

Ms. Veronica Lambert,
1 Ormonde Terrace,
Blackhorse Avenue,
Dublin 7.

15th June 2004

**Re: 04 009: Children and young people's experience of hospitalisation**

Dear Ms. Lambert,

Thank you for your submission to the Ethics Committee. The committee was very impressed with the comprehensiveness of the documentation, which includes consent from the hospital Medical Board.

Ethical approval is now given to proceed with this study.

Best wishes with your research.

Yours sincerely,

# APPENDIX 8

# OVERVIEW OF ETHICAL APPROVAL PROCESS

| Date | Process | Response | Outcome |
|---|---|---|---|
| 3rd Feb 04 | Comprehensive ethics application submitted to the University School of Nursing Ethics Advisory Committee | 20th Feb 04 | Change word 'partake' to 'take part' on child information sheets and state interviews will be tape-recorded. Provide greater rationale for various data collection methods. |
| 21st Feb 04 | Letter submitted to the University School of Nursing Ethics Advisory Committee addressing their recommendations. | 23rd Feb 04 | Proceed to the University Faculty of Health Sciences Ethics Committee |
| 27th Feb 04 | Comprehensive ethics application submitted to the University Faculty of Health Sciences Ethics Committee | 31st Mar 04 | Clarify parents would attend interviews with children. Confirm approval from Chief Executive Officer, Director of Nursing and Medical Board of research hospital. Formulate separate consent form for older children. |
| 14th Apr 04 | Letter submitted to the University Faculty of Health Sciences Ethics Committee addressing their recommendations. | 19th Apr 04 | University Faculty of Health Sciences Ethics Committee approved the study. |
| 23rd Jan 04 | Chairperson of Children's Hospital Scientific & Ethics Committee contacted to clarify the process of application for ethical approval | 23rd Jan 04 | Process outlined and appropriate application forms to complete sent to me |
| 7th Feb 04 | Comprehensive ethics application submitted to the hospital Scientific Committee | 12th Mar 04 | Requested statistical clarification for selection & recruitment of child participants and on how I would avoid bias. |
| 1st Apr 04 | Detailed letter clarifying the selection and recruitment of child participants and how I would address bias re-submitted to the scientific committee. | 5th Apr 04 | Scientific committee approved the application |
| 5th Apr 04 | Hospital Scientific Committee forwarded my application to the Hospital Ethics Committee. | 22nd Apr 04 | Hospital Ethics Committee approved once medical board blanket approval obtained. |
| 26th Apr 04 | Letter submitted to Medical Board requesting blanket consent to access child patients | 28th May 04 | Blanket medical board approval received. Suggested I liaise closely with CNM when recruiting children. |
| 15th Jun 04 | Hospital ethical approval received in writing. | | Approval |

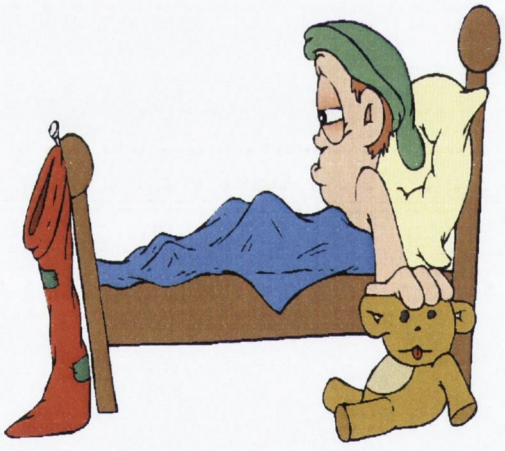
# APPENDIX 9

# INFORMATION PACK FOR THE CHILDREN'S WARD

# Research Study

*Children and Young People's*





*Hospital Project*

# Information Pack for Staff

**Brief Background**

There is a dearth of literature both nationally and internationally addressing children's perceptions of their experiences during hospitalisation. However, a limited number of studies have specifically focused on children in hospital. While acknowledging the limitations of these studies a number of common threads relating to interpersonal relationships, information and involvement have emerged. Collectively these outcomes reveal that children's communication needs were not always met. However, little research effort has focused specifically on communication between children as patients and staff in a children's hospital setting, which represents a gap in current knowledge, thus warrants attention. The purpose of this study is to explore and describe children and young people's experience of communication within the context of a children's hospital setting.

**Researcher**

Veronica Lambert is conducting this research to fulfill the requirements for a PhD Thesis in the School of Nursing and Midwifery Studies at Trinity College. This study is fully supervised by Dr Michele Glacken (Lecturer, Trinity College) and sponsored by the National Children's Office.

**Purpose**

It is envisaged that this research study will advance the three goals of the National Children's Strategy (2000). It will give children a voice in health service matters that affect them. It will provide health care professionals with an enhanced knowledge of the needs of children in hospital so children's lives will be better understood and finally it will ensure that children receive high quality child focused health care services.

**Ethical Approval and Access**

Approval to conduct this study has been granted by the Research Ethics Committee of Trinity College and the Ethics Committee of the [name of hospital] Hospital. The Medical Board, Chief Executive Officer and Director of Nursing have granted access for me to conduct this study.

**Parent and Child Consent**

Parent and child voluntary informed consent will be obtained at the outset and renegotiated on an ongoing basis. Any child can change his/her mind and withdraw from the study at any time or decline from taking part in any specific aspect of the study. Parents are invited to be present at all times throughout the research.

**Research Approach**

This approach involves the researcher spending a considerable amount of time each day (times will vary) on [name of ward] ward with the children and young people. All children and young people admitted to the ward will be invited to take part. The children and young people who agree to take part will be given the option of telling their story through a variety of activities such as informal chats, drawing pictures, keeping a diary and taking various photographs of aspects of the hospital important to them. The researcher will also spend time observing the children interacting with health professionals from the multidisciplinary team and keep a reflective diary and field notes. Part of this study may involve the researcher accessing the child's clinical notes and ward documentation, being present at times of procedures with the child and attending consultations with child participants.

**Confidentiality**

It is important to be aware that the researchers aim is to spend time with the children and young people on the ward and explore their experiences; it is not to assess or evaluate care provided by health professionals. Strict confidentiality will be adhered to. All data will be devoid of any identifying features of person or place. It is important for all personnel to maintain strict child confidentiality in relation to this research study.

**Child Protection**

It must be stressed that absolute confidentiality cannot be guaranteed; this is in relation to child protection. In the case whereby the researcher witnesses any unsafe practice or procedure detrimental to the safety and well-being of any child or if any child discloses

any information that he/she or anyone else is at risk the researcher is obliged under her Code of Professional Conduct (2000) and Children First: National Guidelines for the Protection and Welfare of Children (1999) to report these concerns.

**Researcher Role Switch**

Some people may know the researcher from her previous role as Clinical Facilitator, however her role is now solely as researcher. Thus, despite the fact that the researcher will be spending a considerable amount of time with child participants she does not have a clinical role and will not be involved in performing any aspects of the child's care. However, as an R.C.N the researcher still have an obligation under her Code of Professional Conduct. Should a clinical issue, such as a child falls out of bed, arise the researcher has a code of professional conduct to initiate some intervention until help arrives.

**Researcher Contact Details:**

Please contact the researcher, at any time, should parents/children involved in the study wish to speak with me.

**Veronica Lambert. Tel: 01-8682655 / 087-2483877. Email – lamberv@tcd.ie**

# APPENDIX 10

# POSTER FOR DISPLAY

**Please read the following information**
**Children's Research Study**
**Currently taking place on [name] ward**

# *Children and Young People's Hospital Project*



Veronica Lambert is conducting this research study as part of a PhD Thesis at Trinity College. The study is sponsored by National Children's Office to help advance the goals of National Children's Strategy (2000).

The study involves Veronica spending time every day (times will vary) on [name of ward] ward with children and young people. All children and young people admitted to [name of ward] are invited to take part. The focus of the study is to explore and describe children's perspectives of communication within a children's hospital setting. What are children's information needs and how can we best meet these needs? Children and young people are given the option of telling their story through informal chats, drawing pictures and other activity sheets. Part of the study involves Veronica spending time observing the children as they interact with health professionals from the multidisciplinary team, thus will mean that Veronica will be present at times of some procedures and consultations. It is important to be aware that the researchers aim is to spend time with the children and young people on the ward and explore their experiences; it is not to assess or evaluate care provided by health professionals. Strict confidentiality will be adhered to. All data will be devoid of any identifying features of person or place. Approval to conduct this study has been granted by the Research Ethics Committee of Trinity College and the Ethics Committee of the [name of hospital] Hospital. The Medical Board, Chief Executive Officer and Director of Nursing have granted access for me to conduct this study.

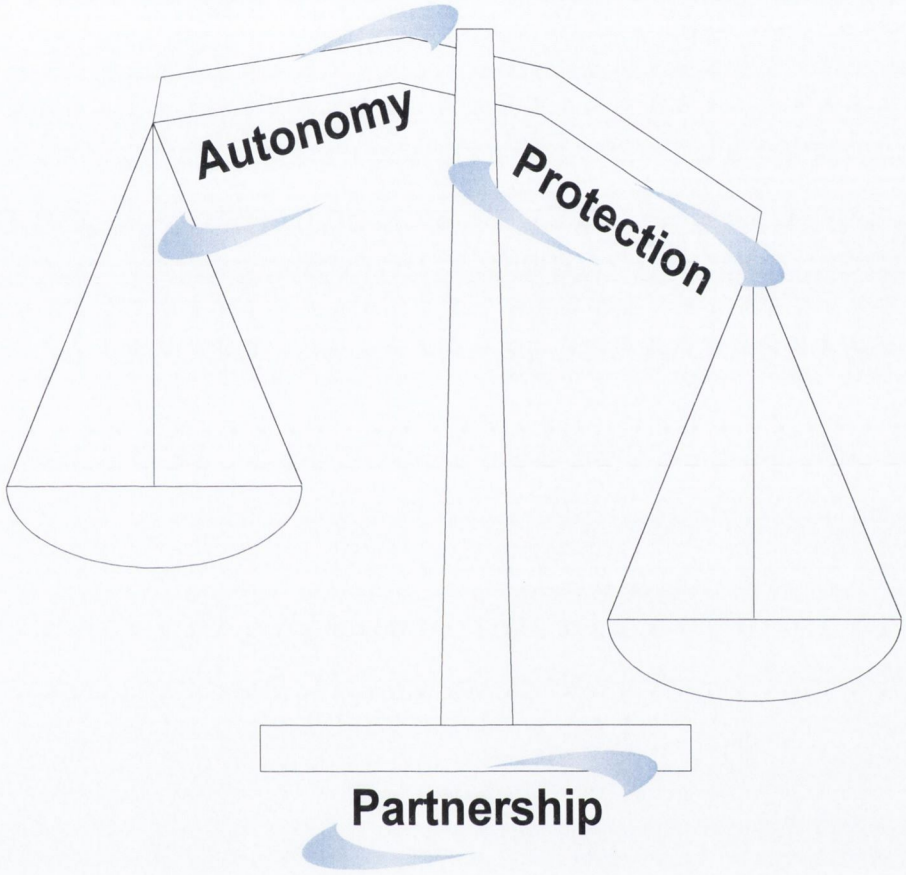
Please contact me, at any time, if you have any questions.

**Veronica Lambert. Tel: 01-8682655 / 087-2483877. Email – lamberv@tcd.ie**

# APPENDIX 11

# CONSENT: CHILD-PARENT-RESEARCHER PARTNERSHIP

# Child-Parent-Researcher Partnership




**"Children are both vulnerable subjects, who need protection from research risks and therapeutic orphans denied access to beneficial research" (Kodish, 2005)**

**Valid Child Assent/Consent**

C – Consider capacity to assent/consent
O - Offer adequate & appropriate information
N – No pressure is applied
S – Seek understanding
E – Evidence in questions / feedback
N – Negotiated continuously
T – Time to think about decision

# APPENDIX 12

## INFORMATION SHEET AND POSTER DISPLAYED ON THE CHILDREN'S WARD

## Who am I?
## (my picture)

Hi, my name is Veronica.

I have to do this project as part of my work for Trinity College where I study.
If you would like to help you can let me know when I visit the ward.

You might have some questions to ask me about the project.
Ask as many questions as you like anytime, now or later.
You might decide you don't want to talk to me. That's OK.
You can change your mind or stop at any time.
You can call me at 087-2483877 or email me at lamberv@tcd.ie at anytime.

# Children and Young People's Hospital Project

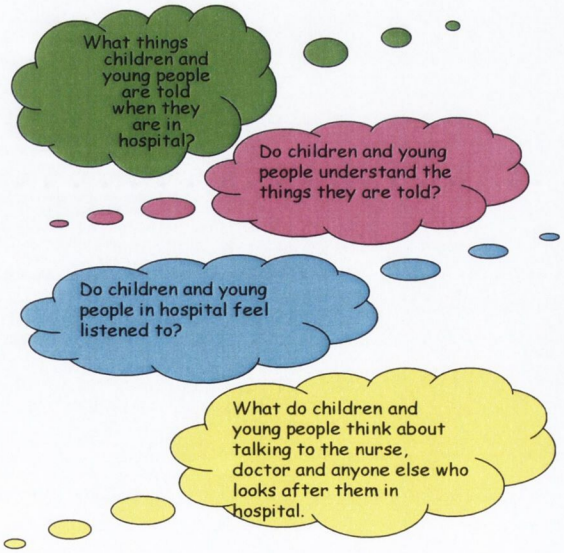





## What is the project about?

Veronica wants to talk to children and young people in hospital.

**Veronica wonders.....**




## How will we do the project?

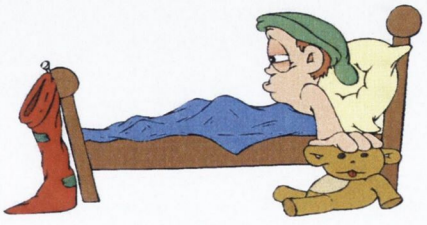
Veronica will visit the ward everyday.
She will just watch you sometimes and talk to you other times about what is happening in hospital.
There are no right or wrong answers.
It's not just talking. You can pick some things to do, like drawing a picture, writing a story or worksheets.

### Do you want to take part?

YOU DECIDE!
You do not have to take part.
It is up to you to say YES or NO.
No one will be mad or upset if you do not want to.
You can change your mind or stop at any time.

### Who else will Veronica tell what you say?

Veronica will only talk about the project with her supervisor in college (who is like a teacher in school).
Your name will be kept secret.
You can choose a pretend name.



# Children and Young People's Hospital Project



## Information for Parents

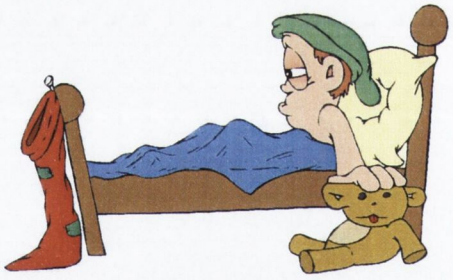
- Hi, my name is Veronica.
- I am doing this research project as part of my study at Trinity College.
- The National Children's Office is sponsoring me.
- You and your child's decision are completely voluntary.
- You or your child can withdraw at any time.
- I am inviting your child to take part because he / she is a patient in the children's ward where this study is taking place.
- Your child's identity will not be disclosed.
- You can call me at 087-2483877 or email me at lamberv@tcd.ie at anytime.

- **What is the project about?**

- My name is Veronica. I am doing a research project with children and young people in hospital.
- I want to find out what children and young people in hospital think about communicating with hospital staff.
- To do this sometimes I just watch how the children and staff talk to each other.
- At other times I chat to the children and young people about what they think about things they are told in hospital.
- Do they understand the things they are told? Can the way they are told things be improved?

The Hospital Ethics Committee has reviewed and given approval for this project to take place.





- **I am seeking your permission to allow me to invite your child / young person to take part.**
- **I will not interfere with your child's care and you can be present at all times.**
- **If you agree I will ask you to sign a consent form. I visit the ward most days at different times and can explain this more. When I visit you can ask me any questions or raise concerns you may have. If you will not be present on the ward and have any concerns about my presence on the ward please telephone me at any time (087-2483877).**

I will not interfere with your child's care and you can be present at all times.

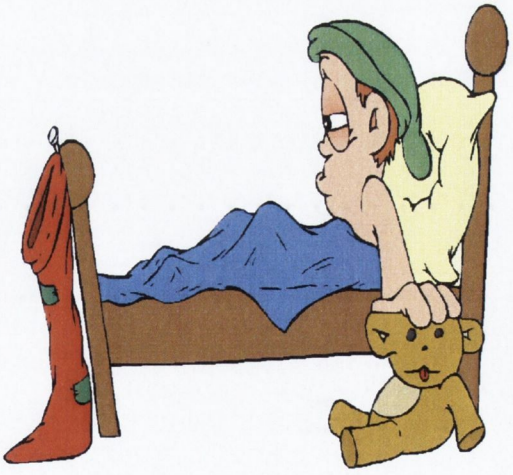
# Children and Young People's Hospital Project

## Would you like to help?



Veronica is doing a project with children and young people in hospital.
She wonders what things children and young people are told when in hospital.
Do children and young people understand the things they are told?
Do they feel listened to?
How could the way children and young people are told things be made better?

If you would like to help Veronica you will see a newsletter on the ward to find out more.
Veronica will visit the ward everyday. You will be able to talk this project over with Veronica when she visits.
You do not have to take part you decide - Yes or No.



Veronica Lambert
Tel: 01-8200073 / 087-2483877 Email - lamberv@tcd.ie

# APPENDIX 13

# PARENT INFORMATION SHEET

## Parent Information Sheet

### Introduction

You are invited to give permission for your child to take part in a research study. This study is to explore children's views of communicating with hospital staff within the children's ward.

The purpose of the study is to give children a voice and listen to what they have to say. This research is sponsored by the National Children's Office and aims to help advance the governments 10 year plan (National Children's Strategy published in 2000) to do things to make children's lives in Ireland better.

Ms Veronica Lambert is conducting this research to fulfil the requirements for a PhD Thesis in the School of Nursing and Midwifery at the University of Dublin, Trinity College. This research study is fully supervised by Dr Michele Glacken.

Your child has been selected to take part because s/he has been admitted to the children's ward at the time of the study.

I ask that you read this document carefully, take time to think it over and ask any questions you may have before agreeing for your child to be approached to take part in the study. Please also discuss it over with your child. A separate information sheet has been supplied for your child.

### Procedure

This research study is taking place on the children's ward (name of ward) in (name of hospital). Here Veronica works as a researcher with the children. Veronica visits the ward most days at different times. Sometimes she watches the children talking with hospital staff and sometimes she chats with the children to gather their views about talking with the hospital staff.

Children are given the option of telling their story through a variety of activities such as informal chats, drawing pictures, writing a story and completing some activity sheets. When watching the children it may involve me being present at times of procedures and doctor/nurse consults. Part of this study may also involve Veronica accessing your child's clinical notes (with your permission). This will allow Veronica to gain background demographic details. However, no clinical details will be disclosed and your child anonymity guaranteed.

**You are invited to be present throughout the entire research process should you so wish.**

### Risks/Benefits

It is believed that this research holds very low risks. However, your child may become upset especially if questions trigger deeply distressing experiences or feelings about hospital. Should

this happen Veronica will provide immediate comfort and reassurance; the research procedure will be stopped and appropriate assistance sought from members of the multidisciplinary team of the hospital.

While this study may have no direct benefit to your child, it does allow your child to be involved in a decision making process and to be given an opportunity to voice his/her opinion. It is believed that knowledge may be gained that will have clear benefits for other sick children in hospital in the future. It is believed that it will help all hospital staff to understand and help children to make hospital a more pleasant and child centred experience.

Approval to conduct this study has been confirmed with the research Ethics Committee of the University of Dublin, Trinity College and the Ethics Committee of the (name) Hospital.

**Confidentiality**

No real names will be recorded on any pieces of information gathered. This includes your child drawings, writings and Veronica's notes.

All information gathered will be stored locked in a secure place. No one other than Veronica and her supervisor will have access to any of the information collected from your child. Information collected from your child will be used for the research purpose intended only.

Steps will also be taken to disguise the identity of your child in the research report (this includes the researchers thesis, all reports to the National Children's Office, articles for publication and presentations at any conferences), by assigning fictitious names to all children involved. All information gathered will be destroyed on completion of the study.

In the case whereby the researcher witnesses any unsafe practice or procedure detrimental to the safety and well-being of your child or if your child discloses any information that s/he or anyone else is at risk the researcher is obliged under her Code of Professional Conduct (2000) and Children First: National Guidelines for the Protection and Welfare of Children (1999) to report these concerns, however in the event of this happening you will be fully informed and involved.

**Voluntary Participation**

Agreeing for your child to take part in the study is entirely voluntary. You and your child agreement to take part will be renegotiated on an ongoing basis. Your child can change his/her mind and withdraw from the study at any time (even after the

study is underway) or decline from taking part in any specific aspect of the study and s/he does not have to say why. If you or your child do refuse or withdraw s/he will still get the best care available to him/her.

Your child will be fully involved in and supported in the decision making process to take part in the study or not. Assurance will be given to your child (once your consent is given) that it is up to him/her to decide whether to take part in this project. Separate information sheets and consent forms have been prepared for your child. It is important that you discuss it over with your child.

It is vital that you do not feel compelled to take part with the view that your child will receive better care and that you truly understand the role of Veronica as researcher and not as a nurse. This research is completely separate from the care your child receives in the hospital. Your child wishes will be respected at all times throughout the entire research project.

**Contacts and Questions**

Please take time to think about your child taking part in the study. I will visit the ward daily to discuss the study and to hear you and your child's decision whether you wish to take part or not.

Should you agree for your child to be invited to take part it will involve you signing a consent form. You will be given a copy of this form to keep.

**If you have any questions now or later please do not hesitate to contact me.**

On completion of this study a summary of results will be made available to you if you so wish.

Researcher: Veronica Lambert - PhD Student,
School of Nursing & Midwifery, Trinity College.
Tel: 01 8200073/087 2483877.
Supervisor: Michele Glacken

# APPENDIX 14

# PARENT CONSENT FORM

**Parent Consent Form**

I,.....have been asked to allow my child .....to take part in the above named research study. I understand that the purpose of this study is to listen to what children have to say about communication in hospital. I am aware that this study is sponsored by the National Children's Office and aims to help advance the governments 10 year plan (National Children's Strategy published in 2000) to do things to make children's lives in Ireland better.

Ms Veronica Lambert, who is conducting this research to fulfil the requirements for a PhD Thesis in the School of Nursing and Midwifery at the University of Dublin, Trinity College, has explained this study to me.

I understand that my child has been selected to take part because s/he has been admitted to the children's ward at the time of the study. I am aware that Ms Lambert will be visiting the ward on a daily basis. I understand that my child will be given the option of telling his/her story through a variety of activities such as informal chats, drawing pictures, writing a story or doing some activity sheets. I am also aware and agree that part of this study will involve the researcher accessing my child's clinical notes. I understand that I can be present throughout the entire research process, should I so wish.

I am aware that this research holds very low risks. However, I do understand that it is possible that my child may become upset if questions trigger distressing experiences or feelings about hospital. Should this happen the researcher will provide immediate comfort and reassurance to my child, the research will be stopped and assistance will be sought from members of the multidisciplinary team of the hospital.

I understand that while this study may have no direct benefit to my child, it does allow my child to be involved in a decision making process and to be given an opportunity to voice his/her opinion. I am aware however that knowledge may be gained that will have clear benefits for other sick children in hospital in the future.

I have been fully informed that no real names will be recorded on any pieces of information gathered and that steps will be taken to disguise the identity of my child in all the research reports. I am aware that all information gathered will be stored locked in a secure place and that no one other than the researcher and her supervisor will have access to any of this information. I have been informed that information collected from my child will be used for the research purpose intended only.

I understand that in the event whereby the researcher witnesses any unsafe practice or procedure detrimental to the safety and well-being of my child or if my child discloses any information that s/he or anyone else is at risk the researcher is obliged under her Code of Professional Conduct (2000) and Children First: National Guidelines for the Protection and Welfare of Children (1999) to report these concerns, however in the event of this happening I will be fully informed and involved.

I understand that agreeing for my child to take part in this study is entirely voluntary. I understand that my child can change his/her mind and withdraw from the study at any time (even after the study is underway) or decline from taking part in any specific aspect of the study and s/he does not have to say why. I do not feel compelled to take part with the view that my child will receive better care. I fully understand the role of Ms Lambert as researcher and not as a nurse. I understand that this research is completely separate from the care my child receives in the hospital. I have been informed that my child wishes will be respected at all times. I understand that agreeing to take part means that I am willing to allow my child to be invited to take part in this study.

**Declaration: Parent**
This study and this consent form have been explained to me. I have read this consent form. I have had the chance to ask questions and the researcher has answered all my questions to my satisfaction. I understand what will happen if I agree for my child to be part of this study. I freely and voluntarily agree for my child to be invited to be part of this research study. I understand that my child and I may withdraw from the study at any time.
Upon signing this form I will receive a copy to keep.
I willingly consent to my child's participation in this research study.

**Signature of Parent**.....
**Date/Time**.....**Contact Details**.....

**Declaration: Researcher**
I have explained the nature, purpose, procedures, benefits and risks of this research study. I have offered to answer any questions and have fully answered such questions. I believe that the parent(s) understand my explanation and has freely given informed consent for his / her child to be invited to take part in this research study.

**Signature of Researcher**.....
**Date/Time**.....

Researcher: Veronica Lambert - PhD Student, School of Nursing & Midwifery, Trinity College. Tel: 01 8200073/087 2483877.

# APPENDIX 15

# INFORMATION SHEET FOR CHILDREN

## Would you like to take part in a project?



My name is Veronica and I am doing a project about what children and young people think about things they are told when in hospital. I have to do this project as part of my work for Trinity College where I study. I am asking you to join because you are a patient in hospital so you can tell me what it is like.





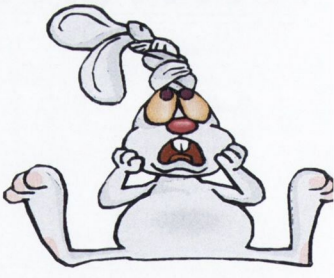
## What will you do in the project?

This project will take place at the hospital. I will visit the ward everyday when you are in hospital. I will just watch you sometimes and talk to you other times about what is happening in hospital. You can pick some things to do, like drawing a picture, writing a story or doing some worksheets. You can decide.



## What things may bother you about the project?

You might feel tired at times; this is because you feel sick as well. So remember if you just want to be on your own to rest ask Veronica to STOP or TAKE A BREAK. You might feel sad if you remember things that you did not like, this is okay you can talk to me about these if you want to. I will try not to let this happen.





## What's good about this project?

This project is good because you can have your say. It is important that you know that this project may not help you when you are in hospital but what I learn from the project may help other children in hospital in the future.

## Who else will Veronica tell about what I say?




Veronica will only talk about her project with her supervisor in college (who is like a teacher in school). She will not tell her your name this will be kept secret. If something you say worries Veronica about your safety or about someone else's safety, she might have to tell her supervisor. This is to keep all children safe. Veronica will talk about this with you first before she talks to someone else.



## Do you want to take part or not? - YOU DECIDE!

You do not have to take part in this project. It is up to you to say YES or NO. No one will be mad or upset if you do not want to. If you say YES, you can change your mind later and STOP AT ANY TIME.

## Before deciding to help with this project?




Take time to think. Talk about this project with your Mam, Dad, brothers and sisters before you say YES or No.



## Do you have any questions?

Ask as many questions as you like at anytime, now or later.

**If you decide to say YES to take part in this project, you will be asked to sign an O.K form.**

Researcher: Veronica Lambert - PhD Student,
School of Nursing & Midwifery, Trinity College.
Tel: 01 8200073 / 087 2483877.
Supervisor: Michele Glacken

# APPENDIX 16

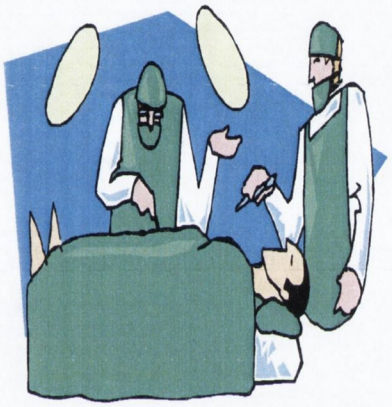
# INFORMATION SHEET FOR YOUNG PEOPLE

**Children and Young People's Hospital Project**

**Newsletter for Young People**

Hi, my name is Veronica and I am inviting you to take part in a project. I want to find out what you think about things you were told about while in hospital, like what was happening to you and your illness. Did you understand what you were told? Did you get to have a say and did you feel you were listened to?

I have to do this project as part of my work for Trinity College where I study. I am asking you to join because you are a patient in hospital so you can tell me what it is like.



This project will take place at the hospital. I will visit the ward everyday when you are in hospital. Sometimes I just 'hang-out' and watch what is going on. Other times I chat to children and young people about what they think about what's going on? You can say what you think by talking to me or by doing other things such as writing and drawing.

You might feel tired at times; this is because you feel sick as well. So remember if you just want to be on your own to rest ask Veronica to STOP or TAKE A BREAK.

It is important that you know that this project may not help you when you are in hospital but what I learn from the project may help other children and young people in hospital in the future.

Veronica will only discuss her project with her supervisor in college but she will not tell her your name, this will be kept private.



**It is completely up to you if you want to take part or not – YOU DECIDE!**

You do not have to take part in this project. It is up to you to say YES or NO. If you say YES you can change your mind later and STOP AT ANY TIME.

**Do you have any questions?**

Ask as many questions as you like at anytime, now or later.

**If you decide to say YES to take part in this project you will be asked to sign a consent form. You will get copy of this form to take home.**

# APPENDIX 17

# CONSENT FORM FOR CHILDREN

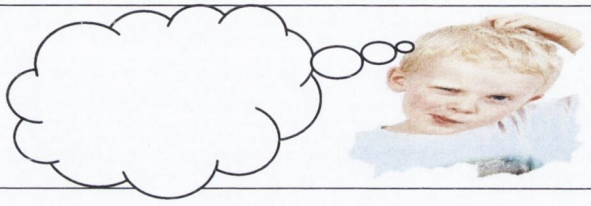
## Children and Young People's Hospital Project



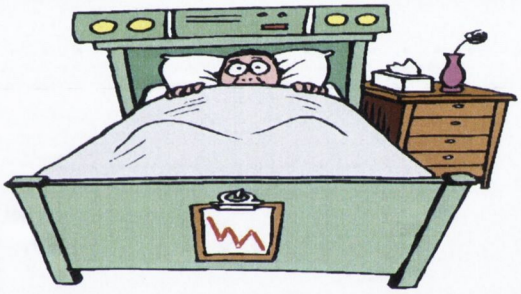
I,_____ have been asked to be in this project. It is about children in hospital.

Veronica has explained it to me.

Veronica has told me this project is to learn about what children think of the things they are told about in hospital.



This project will take place at the hospital.
I know that Veronica will visit the ward everyday. I am happy for Veronica to watch me sometimes and talk to me sometimes about what is happening in hospital.





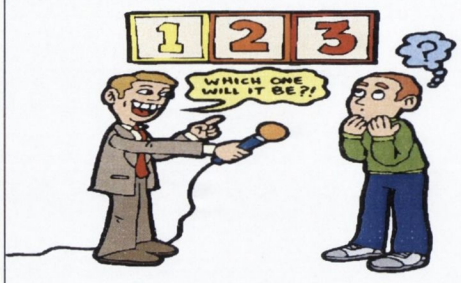
I can pick some things to do, like, draw a picture, write a story or do some worksheets. Veronica has explained these things to me. I can decide.

If I feel tired or sad, or just want to be on my own I can ask Veronica to STOP or TAKE A BREAK.




Page 1

I know this project may not help me but what they learn from the project may help other children in hospital.




I know I do not have to do thi project.

IT'S UP TO ME!

No one will be mad at me if I not want to, or if I decide to STOP AT ANY TIME.

I know I can ask Questions Now or Later.



I have been promised that anything Veronica learns about me will be kept as secret as possible. Veronica has talked about this with me.





For
More Information
More Questions
About this project
Phone Veronica - 01-8200073/087-2483877



**I really want to help in this project**
**Child's Signature** .....
**Researcher's Signature**.....
**Date / Time** .....

**THE END**

# APPENDIX 18

# CONSENT FORM FOR YOUNG PEOPLE

**Children and Young People's Hospital Project**
**Young People's Consent Form**

I, have been asked to be in this research project. Veronica has told me that this project is to learn about what young people think about things they are told in hospital.

I know that Veronica will visit the ward everyday. I am happy for Veronica to 'hang out' and watch what is going on and to talk to me about what is happening in hospital.

I can choose some things to do, like, draw a picture, write a story, do some worksheets or just talk to Veronica. I can decide.

If I feel tired or unhappy, or just want to be on my own I can ask Veronica to STOP or TAKE A BREAK.

I know this project may not help me but what they learn from the project may help other children in hospital.

I know I do not have to take part in this project. No one will be angry, if I do not want to or if I decide to STOP AT ANY TIME.

I have been promised that anything Veronica learns about me will be kept as secret as possible.

I know I can ask Questions, Now or Later.

**I really want to take part in this research project**

**Signature of Young Person.....**

**.**

**Signature of Researcher.....**

**Date / Time.....**

# APPENDIX 19

# STATUTORY DECLARATION

## Research with Children

# Statutory Declaration

## 'No Previous Offences Against Children'

Prior to undertaking my research study with children, I wish to declare that I, Veronica Lambert, have had no previous record of offences against children and have not, in the past been excluded from working with children. I have previously received Garda Clearance prior to my employment as a Registered Sick Children's Nurse.

Signature: Veronica Lambert

Date: 28th May 2004

Submitted to School of Nursing & Midwifery Studies, Trinity College, May 2004

# APPENDIX 20

# FIELD NOTE EXTRACTS: PARENT INTERVENTION

**Parents Intervening: Impact on Rapport Building**

While I chatted with Mark (6 years) his mother was present. Mark was going to draw and as I was setting up the table for him he showed me his *Shrek* two annual. This led us to talk about the film for a few minutes. Then, Mark's mother took the annual away from Mark saying, ok put it down ((I didn't feel happy or comfortable with this intervention by his mum. Could this inhibit my ability to build rapport with Mark because social chit chat alongside my informal conversations and participatory activities with children are important and invaluable to build rapport)). (Field Notes Nov 04).

**Parent Presence: Uncomfortable, Cautious and Apprehensive**

When I spoke with Mark (6 years) his mother was present. During my conversation with Mark his mum interjected at a few points to rephrase questions I had posed using different terminology. Mark's mother also answered some questions on behalf of Mark. ((I feel a little apprehensive and cautious with his mother listening. I'm not sure why. I am self-conscious of myself as I'm still in the early stages and not really sure what I'm looking at or for thus what I need to be engaging with the children about? Am I worried about what she will think of me? I am not sure why I am feeling like this, especially considering mum was helpful to assist me with rephrasing some questions in terms of language. Maybe this made me feel a little uncomfortable in that I should be able to communicate effectively with a 6 year old considering I am a children's nurse. Thus, perhaps I feel by mum intervening and assisting that I am in some way exposing some incompetence. However, does this mother not know her child better, in terms of what he can understand and what words he used more regularly in his everyday life? Maybe it was also the fact that Mark's mother on occasions interjected and answered on his behalf, I was not comfortable with this as this affected me hearing the voice of the child, in this instance Mark)) (Field Notes Nov 04)

**Parent Intervening: Subtle Signs of Parent Consent Refusal**

While I was chatting, just informally about rugby, with Mike (12 years) his mum arrived. It was now about 9.40 hours. I chatted briefly with Mike's mum as well about the weekend. Mum started getting Mike's schoolbooks out, it was time for schoolwork again

she said; the teacher was coming at 10am. ((Was this my cue to leave?)) (Field Notes Nov 04).

While I chatted with Emily (7 years) (we were both sitting on the end of her bed) Emily's mum arrived back and asked me how you getting on, you getting loads of information? ((I felt a little bit awkward)). Emily's mum went on to say, 'she's not well today she's very tired and washed out looking'. ((I got the impression that was my cue to leave. Even though mum had signed a consent form and allowed me access to talk to her daughter I really got the impression she did not want me to, at least today anyway. It is difficult to talk to children when you get this vibe from parents, it did not feel right. I felt maybe she had agreed but did not really want her daughter to take part.)) (Field Notes Dec 04).

**Parent Intervening: Assisting with Re-Phrasing**

Spoke with Stephen 11 years who was awaiting surgery pre-operative strabismus repair. Mum stayed for the interaction I had with Stephen, however she did not interrupt nor answer for Stephen but helped with rephrasing questions to assist in his understanding of what I was saying. (Field Notes Feb 05)

# APPENDIX 21

# CHILD PARTICIPANT CHARACTERISTICS

## Child Participant Characteristics

| Child (pseudonym) | Age (year) | Sex | Reason for Admission (M = Medical / S= Surgical) | Length of stay (nights) | Mode of admission | PH | Education Level P=primary S=secondary |
|---|---|---|---|---|---|---|---|
| Annette | 8 | F | Rash on legs: HSP (M) | 2 | ED | No | P 3rd class |
| Deirdre | 12 | F | Tonsillitis (M) | 3 | ED | No | S 1st year |
| Siobhan | 10 | F | Asthmatic attack (M) | 6 | ED | Yes | P 4th class |
| Tom | 13 | M | Appendectomy (S) | 7 | ED | No | S 2nd year |
| Maria | 10 | F | Appendectomy (S) | 2 | ED | Yes | P 4th class |
| Yvonne | 13 | F | Chest pain (M) | 1 | Elective | Yes | S 1st year |
| Mark | 6 | M | Eye Surgery (S) | 3 | Elective | Yes | Senior infant |
| Brian | 10 | M | Asthma attack (M) | 2 | ED | Yes | P 5th class |
| Chloe | 16 | F | Arthrodesis CTEV (S) | 4 | Elective | Yes | S Transition |
| Jodie | 9 | F | Appendectomy (S) | 4 | ED | No | P 3rd class |
| Rebecca | 11 | F | Appendectomy (S) | 4 | ED | No | P 5th class |
| Freddie | 10 | M | Parotiditis (M) | 5 | ED | No | P 4th class |
| Mike | 12 | M | Wound infection (S) | 30 | Hosp trans | Yes | P 6th class |
| Sonja | 10 | F | Facial cellulitis (S) | 2 | ED | Yes | P 4th class |
| Gary | 11 | M | Appendectomy (S) | 2 | ED | Yes | P 6th class |
| Sean | 10 | M | Abdominal pain (S) | 3 | ED | No | P 5th class |
| Damien | 6 | M | Remove metal plate tibia (S) | 2 | Elective | Yes | Junior infant |
| Aoife | 10 | F | Appendectomy (S) | 7 | ED | No | P 4th class |
| Lee | 6 | M | Left patella stabilisation (S) | 4 | Elective | Yes | Senior infant |
| Colm | 13 | M | Tympanoplasty (S) | 2 | Elective | Yes | S 1st year |
| Holly | 6 | F | Asthmatic attack (M) | 2 | ED | Yes | Senior infant |
| Emily | 7 | F | Consolidation (M) | 7 | OPD | Yes | P 1st class |
| Katie | 12 | F | Respiratory tract infection Cystic Fibrosis (M) | 14 | OPD | Yes | Unknown |
| Sinead | 9 | F | Appendectomy (S) | 4 | ED | No | P 3rd class |
| Orla | 10 | F | Seizures (epilepsy) (M) | 3 | ED | Yes | P 4th class |
| Joanne | 14 | F | Seizures (M) | 3 | ED | Yes | Unknown |
| Mary | 8 | F | Appendix mass (S) | 10 | ED | No | P 2nd class |
| Frank | 11 | M | Tonsil bleed (S) | 3 | ED | Yes | P 5th class |
| Ann | 8 | F | Strabismus repair (S) | 2 | Elective | No | P 2nd class |
| Donal | 12 | M | Pancreatitis | 6 | ED | No | S 1st year |
| Michael | 10 | M | Constipation (S) | 20 | ED | Yes | P 4th class |
| Shane | 13 | M | Episcleritis (S) | 5 | Elective | Yes | S 1st year |
| Kelly | 13 | F | High blood sugar Diabetes Mellitus (S) | 1 | ED | Yes | S 1st year |
| Rosie | 11 | F | Asthmatic attack (M) | 2 | ED | Yes | P 5th class |
| Joe | 13 | M | Cruciate ligament tear (S) | 3 | ED | No | S 1st year |
| Helen | 12 | F | Respiratory tract infection Cystic Fibrosis (M) | 14 | OPD | Yes | Unknown |
| Sue | 12 | F | Constipation (M) | 4 | ED | No | P 6th class |
| Stewart | 13 | M | Eczema (M) | 7 | ED | Yes | S 1st year |
| John | 13 | M | Perforated Appendix (S) | 24 | ED | No | S 1st year |
| Maureen | 12 | F | Mc Brides Procedure (S) | 2 | Elective | Yes | P 6th class |
| Rachel | 9 | F | Appendix mass (S) | 9 | ED | Yes | P 4th class |
| Gavin | 6 | M | Irritable hip (S) | 2 | ED | No | Senior infant |
| Denzel | 10 | M | Appendicitis (S) | 2 | ED | No | P 3rd class |
| Luke | 11 | M | Debulk lymphangioma (S) | 9 | Elective | Yes | P 5th class |
| Stephen | 11 | M | Strabismus repair (S) | 2 | Elective | No | P 5th class |
| Collette | 6 | F | Tonsillectomy (S) | 2 | Elective | Yes | Senior infant |
| Ciara | 13 | F | Pharyngoplasty (S) | 3 | Elective | Yes | S 1st year |
| Rory | 12 | M | Fractured pelvis (S) | 28 | ED | No | P 6th class |
| Kerry | 13 | F | Quinsy (S) | 6 | OPD | Yes | S 1st year |

ED = Emergency Department; OPD = Out-Patients Department; Hosp Trans = Hospital Transfer. PH = Previous Hospitalisation.

# APPENDIX 22

# CHILD PARTICIPANTS PREVIOUS HOSPITAL ADMISSIONS

**Child Participants Previous Hospital Admissions (overnight stays)**

| Child | Age | Previous Hospital Overnight Admission |
|---|---|---|
| Siobhan | 10 | Once before with asthma (unknown how long ago) |
| Maria | 10 | At 7 years hospitalised for 3 weeks with burns and at 8 years hospitalised for 6 weeks for weight loss. |
| Yvonne | 13 | Appendectomy within the last year |
| Mark | 6 | Similar surgery every few weeks |
| Brian | 10 | Fractured elbow one night stay at 3 years of age |
| Chloe | 16 | Previous operations on foot at age of 3 and 5 (first time in this hospital) |
| Mike | 12 | Spinal surgery (5 years ago) |
| Sonja | 10 | Number previous admissions |
| Gary | 11 | At 3 years of age hospitalised for 2 nights with pneumonia |
| Damien | 6 | Last year 5 night stay for fractured tibia |
| Lee | 6 | Number of admissions in last year with asthma/pneumonia (first time in this hospital) |
| Colm | 13 | Previous admission when a baby |
| Holly | 6 | Previous admissions with asthma (unknown how long ago) |
| Emily | 7 | Numerous previous admissions |
| Katie | 12 | Couple of times a year since birth |
| Orla | 10 | Once before when diagnosed with epilepsy (first time in this hospital) |
| Joanne | 14 | Numerous previous admissions with seizures (since birth) |
| Frank | 11 | Yes for psoriasis when younger (first time in this hospital) |
| Michael | 10 | 3 admissions in last 2 years, range 2-9 nights, with similar problem |
| Shane | 13 | Earlier this year 4 nights similar problem |
| Kelly | 13 | Hospitalised at time of diagnosis of diabetes now mostly OPD |
| Rosie | 11 | Aged 3 years pyrexia / appendectomy |
| Helen | 12 | Couple of times a year since birth |
| Stewart | 13 | Yes with eczema (unknown how long ago) |
| Maureen | 12 | Previous operations on foot when younger (first time in this hospital) |
| Rachel | 9 | Previous eye surgery (first time in this hospital) |
| Luke | 11 | 5 years ago similar problem |
| Collette | 6 | One and 2 years ago with UTI and 4 years ago with croup |
| Ciara | 13 | Last operation 4 years ago, also at age 7 and 8 months of age |
| Kerry | 13 | 2nd admission in a week |

# APPENDIX 23

# RESEARCH TIME SPENT IN THE CHILDREN'S WARD

**Research Time Spent in the Children's Ward**

I have removed specific dates to maintain participant confidentiality.

| Date | Date | Time | Hours | Cum. Total |
|---|---|---|---|---|
| **Week One** | Monday | 10.00-12.00 | 2 | 2 |
| **Oct-04** | Tuesday | 07.45-11.00 | 3.15 | 5.15 |
| | | 18.00-19.00 | 1 | 6.15 |
| | Wednesday | 08.00-15.00 | 7 | 13.15 |
| | Thursday | 11.00-12.00 | 1 | 14.15 |
| | | 15.00-16.00 | 1 | 15.15 |
| | Friday | 16.00-17.00 | 1 | 16.15 |
| **Week Two** | Monday | 11.30-15.30 | 4 | 20.15 |
| **Nov-04** | Tuesday | 12.00-13.00 | 1 | 21.15 |
| | | 14.00-17.00 | 3 | 24.15 |
| | Wednesday | 16.00-17.00 | 1 | 25.15 |
| **Week Three** | Tuesday | 10.00-15.00 | 5 | 30.15 |
| **Nov-04** | | 17.00-18.00 | 1 | 31.15 |
| | Wednesday | 12.00-16.00 | 4 | 35.15 |
| | Thursday | 07.30-15.00 | 7.5 | 42.45 |
| | Saturday | 11.00-15.00 | 4 | 46.45 |
| | Sunday | 07.30-10.00 | 2.5 | 49.15 |
| **Week Four** | Tuesday | 16.00-18.00 | 2 | 51.15 |
| **Nov-04** | Wednesday | 08.30-16.30 | 8 | 59.15 |
| | Thursday | 10.00-12.00 | 2 | 61.15 |
| | | 14.00-17.00 | 3 | 64.15 |
| | Friday | 13.00-18.00 | 5 | 69.15 |
| | Sunday | 11.00-14.00 | 3 | 72.15 |
| **Week Five** | Monday | 08.00-10.00 | 2 | 74.15 |
| **Nov-04** | | 16.00-18.00 | 2 | 76.15 |
| | Tuesday | 14.00-18.00 | 4 | 80.15 |
| | Wednesday | 08.00-18.00 | 10 | 90.15 |
| | Thursday | 13.00-17.00 | 4 | 94.15 |
| | Saturday | 12.00-13.00 | 1 | 95.15 |
| **Week 6** | Wednesday | 10.00-11.00 | 1 | 96.15 |
| **Dec-04** | | 14.00-16.00 | 2 | 98.15 |
| | Thursday | 09.30-14.30 | 5 | 103.15 |
| | | 16.30-19.00 | 2.5 | 105.5 |
| | Friday | 08.00-11.00 | 3 | 108.5 |
| | | 16.00-17.00 | 1 | 109.5 |
| **Week 7** | Wednesday | 13.00-16.00 | 3 | 112.5 |
| **Jan-05** | Thursday | 08.00-15.30 | 7.5 | 120 |
| | Friday | 14.00-16. 30 | 2.5 | 122.5 |
| | Saturday | 11.30-14.30 | 3 | 125.5 |

| | | | | |
|---|---|---|---|---|
| | Sunday | 10.30-14.30 | 4 | 129.5 |
| **Week 8** | Monday | 12.00-16.00 | 4 | 133.5 |
| **Jan-05** | | 18.00-18.30 | 0.5 | 134 |
| | Tuesday | 11.00-15.00 | 4 | 138 |
| | | 16.00-18.00 | 2 | 140 |
| | Wednesday | 08.30-15.30 | 7 | 147 |
| | Thursday | 08.00-12.00 | 4 | 151 |
| | | 16.00-18.00 | 2 | 153 |
| **Week 9** | Monday | 12.00-16.00 | 4 | 157 |
| **Jan 05** | Tuesday | 14.00-18.00 | 4 | 161 |
| | Wednesday | 10.00-18.00 | 8 | 169 |
| | Thursday | 09.00-10.00 | 1 | 170 |
| | Friday | 08.00-18.00 | 10 | 180 |
| | Saturday | 10.00-13.00 | 3 | 183 |
| **Week 10** | Monday | 10.00-12.00 | 2 | 185 |
| **Feb 05** | Tuesday | 08.00-17.00 | 9 | 194 |
| | Wednesday | 09.00-11.00 | 2 | 196 |
| | | 15.00-17.00 | 2 | 198 |
| **Week 11** | Monday | 09.30-15.30 | 6 | 204 |
| **Feb 05** | Tuesday | 14.00-19.00 | 5 | 209 |
| | Wednesday | 08.00-15.00 | 7 | 216 |
| | Thursday | 08.00-17.30 | 9.5 | 225.5 |
| **Week 12** | Tuesday | 08.00-12.00 | 4 | 229.5 |
| **Feb 05** | Wednesday | 08.30-13.30 | 5 | 234.5 |
| | Thursday | 08.00-13.00 | 5 | 239.5 |
| | | 14.00-15.00 | 1 | 240.5 |
| | Friday | 10.00-12.30 | 2.5 | 243 |
| | Saturday | 10.00-12.00 | 2 | **245 hours** |

# APPENDIX 24

# GUIDANCE ON WHAT TO OBSERVE

## What to Observe?

| **Spradley (1980)** | **Merriam (1998)** |
|---|---|
| Space: physical setting/layout sketches | Physical Setting: what's the scene/context? |
| Actors: people involved | Participants: who's in the scene? Roles? |
| Activities: activities of the people involved | Activities & Interactions: What's going on? Sequence of activities? |
| Objects: physical elements e.g. furniture | Conversation: what's the content of conversation?<br>Who talks to whom? Who listens? |
| Act: individual people actions | Subtle factors: Unplanned activities?<br>What does not happen? Non-verbal. |
| Events: particular occasions e.g. meetings | Your own behaviour: You are part of the scene.<br>What do you say / do? Role?<br>Do you have observer comments? |
| Time: sequence of events | |
| Goals: what actors attempt to accomplish | |
| Feelings: emotions in particular contexts | |

# APPENDIX 25

# SAMPLE OF OBSERVATIONAL FIELD NOTES

**Sample Observational Field Notes**

I arrived to the ward at 8.30am. The morning nursing report has just finished. The nurses are out on the corridor getting ready for the day ahead. It is breakfast time. I'm down the surgical side standing at the door to the room at the side towards the road. In bed 6 (corner bed just inside the door) I hear a voice call nurse. I looked around but no nurse. A few minutes later two nurses enter the room with a linen trolley. It is bed-making time. The child participant Mike (pseudonym) called out nurse again, one of the nurses went to him. She stood at the side of his bed and leaned over to hear what he had to say. I couldn't hear but the nurse said okay, pulled the curtain around and the second nurse went to help. When they pulled back around the curtains he was sitting up.

After this the two nurses went to child participant Jodie (pseudonym) and one nurse said to the girl 'will you sit out for me?' The girl nodded got up and sat out in the chair while they made her bed. There was no further conversation with the girl, the nurses chatted together while making the bed. *((nurse initiated interaction to request to undertake the bed making task but then limited interaction with child))*

A seconded student entered the room and headed to Mike….she asked '(boy) what do you want for breakfast?' He told her what he wanted…two weetabix. She went off to get it. One staff nurse passed by and said to the same boy 'your breakfast is coming'. *((again nurse initiated interaction, task related to determine child's needs))*

A doctor arrived (dressed in green scrubs and theatre hat). He had two patient charts in his hand. He left one on the bed table at the end of child participant Rebecca's (pseudonym) bed and held the second one in his hand going to Jodie. He walked up along the side of the bed (the bedside rail was up) and asked the girl how she was (she was lying in bed attached to a drip). ((*doctor initiated opening with general open question))* She asked for a drink of water. *((here child's response request for drink .....so someone has come to her and this gave her an opportunity to ask for something she needed).* The doctor said so you're thirsty. ((*the doctor interrupts the child's responses clarifying she is thirsty))* He then asked her was she sore and if it was better. *((here he changes the topic of conversation to pain))* She nodded (yes). He said I'll just get one of the girls (nurses) to come and then I'll have a look. He pulled around the curtains and went to get one of the nurses.

The doctor went to Rebecca (I asked mum and girl if they minded if I listened they agreed to my presence). The girl was lying on the bed. Mum who had been sitting on a chair at bedside stood up, the student nurse who was allocated to the room this morning stood beside mum. At the far side of the bed was the doctor and next to him a staff nurse. The curtains were pulled around. I stood next to the student nurse. *((doctor initiated, purpose examination, postures all standing, mum who was sitting stood up, child lying on bed with adults all standing around her))*
Doctor asked the staff nurse what were observations like overnight did she have temperature ((*prior to examination seeking info from the nurse))*
Staff Nurse said I'll get the chart for you and left.

Doctor asked child was she sore *((asking question seeking information closed question))*
Child (nodded yes) (*(nonverbal limited response from child, yet asked a closed question so answer either yes or no. could child have been intimidated by all adults towering above her))*
Mum spoke saying she's sore when she walks but she's afraid to say anything. *((as child gave limited response mum automatically cut in to give more elaborate information, was the child scared to respond as mum depicted))*
Doctor asked had she gone to the toilet, he directed this question to the girl.
The child didn't answer looked puzzled *((does the child not respond because she doesn't understand or is she afraid as mum suggested))*
Doctor then asked mum did child open her bowels yesterday... *((so when the child didn't respond rather than rephrase or ask for understanding from the child the doctor ask the mother ....so is it easier to talk to parents))*
Mum yes
The staff nurse had returned and the doctor turned and had a look at the observation and I/O chart. He talked to the nurse going through the charts. He then turned back to the child and mum.
Doctor asked mum had child eaten anything *((continues to talk to mum seeking information))*
Mum replied not since yesterday when she vomited what she ate. She is now fasting since midnight.
Doctor asked the girl did she feel like eating (*(turn allocated to child to seek information closed question))*
Child (nodded no).
Doctor then went to examine the girl's tummy, saying I'm just going to feel your tummy. He pulled up her PJ top just enough to expose her tummy and began pressing and feeling moving from one area to another asking is it sore here and here and here the girl would nod yes or no depending on where he was pressing. When he touched the spot that the girl identified as sore, he pressed up and down again asking is it sorer up here or down here, she replied up and then he pressed it in and out really quickly and asked which was sorer girl replied when pressed in. She was grimacing and tears filled her eyes when he was doing this. Mum rubbed her arm. The student went to the sink in the room where there was some paper towel and returned with some and handed it to the girl to wipe her tears.
Doctor told mum we'll probably take her to theatre but told her he'd have to discuss it with (name consultant). He also informed her it would be at the end of theatre list so it wouldn't be until evening. *((doctor provides information to parent regarding the plan....child listening.....see chat I had with Rebecca she was able to relay this information to me)) ((when doctor was talking with mum he was talking across the bed over the child who was lying on the bed))*
Doctor to staff nurse: so stay fasting and keep her on fluids.
Nurse asked doctor to chart the IV fluids. He did this at bedside. Then he turned and said okay I'll be back later.
During this interaction another staff nurse peered in asking is (name of nurse) in there, the staff nurse who was beside the doctor called out yes…do you want the keys. Staff

nurse outside curtain said no…I just want to ask you something when you're ready. The staff nurse replied ill be out in a minute (interruption/distraction).

It's now about 9am. A seconded student was sitting on the arm of a chair leaning on the bedside, which was up, talking to this girl in Jodie. The girls IV pump had started to beep, the seconded student alerted the post registration student to the beeping IV. The post registration student nurse arrives at Jodie's bed and said to the girl, how are you darling..okay. We'll get you a drink of water. She asked the girl, do you want to sit out on the chair darling. The girl nodded yes.
The student attempted to reset the pump and said beeping silly old thing to the girl. She called a staff nurse to check and go through the pump with her again. The staff nurse came in and went through the pump explaining it to the post registration and seconded student. Once finished the staff nurse left and the two students helped the girl out into a chair, they then proceeded to make the bed
The post registration student turned to the girl (once finished making the bed) and asked…are you okay there pet? (she was standing in front of the girl holding onto the arms of the chair in which the girl was sitting facing the girl). The child said something but spoke very quietly the student asked, what. The girl asked for a drink of water. The student replied, okay just a little as only allowed a little bit, she leaned over her to reach for the water on the locker behind her.

The post registration student then went to child participant Chloe (pseudonym) and asked: how are you today? You were zonked yesterday. The girl replied: ya better today. The student asked what she would like for breakfast and helped her sit up in the bed. She then went across to get a bed table from Mike's bed and said to him, can we share this (the table). He said, yes.
*((are you okay/how are you.....what does it mean?))*

10am Mum and dad had arrived at Chloe's bed (they were sitting at the child's bedside). The post registration student went over to them; Chloe was asleep. The student informed the parents that the physiotherapist would be coming later to help get her up out of bed and use the crutches (she had a below knee POP on her right foot) and also they (nurses) would be taking her drain out.

The schoolteacher had arrived. She went to Mike. Mike was in bed with his table in front of him on which lay all his schoolwork. The teacher sat on a chair beside his bed and they were engaged in schoolwork.

11am The post registration student was going through her patients charts on the corridor beside window ledge. The seconded student was with her. She was telling the seconded student about drains (discussing Chloe and the drain removal and its purpose).
The post registration student then asked the seconded student to check Chloe's observations. The seconded student went to Chloe but returned and said she's asleep will I wake her to do them. The post registration student said…yes we're behind they're 10 o'clock observations. The post registration student followed her in and while the seconded student was checking temperature and saturations the post registration student

was checking CMS of toes where POP was, she then called the seconded student down to look at the toes and explained about checking CMS. *((routine and ritual)) ((observations))*

12.30pm Rebecca was lying on her bed, dad was sitting in chair beside bed, the anaesthetist (dressed in green scrubs and hat) arrives to review Rebecca. He walked towards dad, carrying a sheet of paper in his hand (anaesthetic record), he introduced himself to dad. He stood beside dad and said he was asked to see her in case she was going to theatre later. Directed to dad he asked when she (Rebecca) had MRI previously did they put her asleep for it. *((use of word 'she' again in child's presence)) ((seeking information from dad))*
Dad turned towards Rebecca and asked her was she put asleep when she had her MRI. *((dad involved child seeking information from her ? because he didn't really know or was unsure of the answer))*
The anaesthetist then repeated this question this time to Rebecca. *((once dad had involved the child the anaesthetist then allocated a turn to the child, turning his attention briefly to her))*
She nodded yes. *((responds nonverbally to closed question))*
The anaesthetist asked dad when the drip was started pointing towards the IV pump *((anaesthetist turned his attention and questioning back to dad query because of limited response from child))*
Dad replied: Tuesday
The anaesthetist then asked Rebecca was she thirsty *((closed question allocated to child ...so the anaesthetist is going from child to dad allocating each a turn.....but is their a difference ....child asked about physical things affecting them ....dad asked more technical information))*
She nodded no *((limited response to closed question))*
Anaesthetist asked her to stick out her tongue
She did and the anaesthetist leaned down over her to have a look saying okay
*((what was evident in this interaction with the child so far is that the anaesthetist is seeking information and asking questions to fulfil his goals to prepare for putting the child asleep for the operation....rather than addressing the child's needs in relation to being put asleep for the operation))*
The anaesthetist then asked Rebecca did she have any questions *((here the anaesthetist turns his attention to the child's needs))*
She asked: Am I going to have my appendix out? *((so here as everyone prepares the child for theatre it would appear from the child's question that she is till unsure of whether she is having an operation or not....it also shows that if allocated a turn and given an opportunity to ask questions children do have questions to ask...it gives children a say))*
Anaesthetist replied: yes
She then asked: what time *((again child wanted more specific information about when the operation would be.....this is also reflected in children's conversations....why is this so is it so they can prepare themselves))*
Anaesthetist said: I cant say…..hard to say with theatre…okay and left
The girl was texting away on her mobile phone once he had left (her mam)

The seconded student was sitting again beside Jodie on a chair, the bedside remained up (Jodie was now back in bed she had been sitting out earlier). The seconded student was asking her about her pain. She asked was she sore. Jodie nodding yes. The student asked was it a big bit or a little bit sore and used the 1-9scale. Jodie did not answer this question but asked for her mam. The student said I'm sure it won't be long now and she'll be in. Jodie said she said she'd be in at 2pm. The student said well that not to long just two hours. *((Jodie was on her own most of the morning apart from this seconded student checking in on her every so often, she looked sad and slept throughout the morning .....although the seconded student came to check her every so often this child was clearly lonely and sad and bored))*

The pain nurse specialist (dressed in scrubs) entered the room and approached Chloe's parents sitting by her bed. Chloe was asleep. The pain nurse specialist stood at end of bed and spoke to her parents. She explained that Chloe was off her morphine now and actually she had not used any since lunchtime the day before. She told them that she could have Voltarol and this hadn't been given since last night so she could have it again. She said I'll call back later, okay.

14.00hours I arrived back to the ward and the physiotherapist had just arrived and had started to get Chloe up to mobilise. The physiotherapist was at the end of the bed asking the child how did she feel and was she okay to get up (a different physiotherapist had actually visited the ward earlier in the morning but the child was zonked so she had told the parents would call back in afternoon). Chloe said grand ya.
*((interaction initiated by the physiotherapist opening question directed to child, asking child's opinion, negotiating ready to undertake task of mobilising))*
Mum and dad stood up and dad bent down to get crutches from under bed (which the first physiotherapist had brought earlier in the morning). The physiotherapist said to dad, you mind your back. Chloe said ...dads (laughing). Dad handed the crutches to physiotherapist who was standing at the end of the bed. The girl was leaning forward sitting up in the bed watching the physiotherapist. The physiotherapist explained what Chloe had to do and how by demonstrating using crutches. Chloe said okay.
*((physiotherapist providing instructions and information to child, parents are listening in also, practical demonstration also given by physiotherapist))*
The physiotherapist then went up the side of the bed beside Chloe and asked was she feeling sick dizzy
Chloe responded no with a puzzled face.
Physiotherapist asked: have you used crutches before? Chloe: no
Physiotherapist asked: have you stairs at home? Chloe: ya
*((physiotherapist eliciting information from child in order to prepare for task ahead, she is assessing child's previous experience and home environment))*
Physiotherapist: Okay we'll try some steps.
Physiotherapist, Dad and I went out the door of ward at surgical end to where there were some steps.
The physiotherapist demonstrated and explained to the child what she had to do and how to do it.

Dad and I stood at the end of the stairs (just watching saying nothing).
The physiotherapist assisted Chloe to go up and then come down the stairs (explaining again how to do this). As Chloe was going up and coming down she asked was she okay.
Chloe saying yes grand.
On the way back down the steps Chloe said: look at dad (her dad was smiling at her)
Physiotherapist: we'll give your dad the crutches and see how he gets on. *((humour smiling))*
On the way back in the ward door a student nurse who was standing on the corridor said: Chloe well done.
*((praise / encouragement))*
When they got back to bed the physiotherapist explained to the child again to have someone with her first while until got used to it and if she couldn't manage stairs go up and down it on her bum using good leg. The physiotherapist stood at top bed beside child who had got back into bed the mum and dad stood at end of bed.
Physiotherapist then turned to mum / dad explained to them to be with her initially to watch her going up / down stairs.
Physiotherapist also explained to Chloe when the cast comes off you will need physiotherapy then, but not now I'm happy that you ready to go home when doctors are happy. (*(providing information directly to child, physiotherapist stood at top of bed beside child with parents standing at foot of bed))*
Physiotherapist then turned to mum / dad and said contact her then….when cast comes off as she'll need physiotherapy then…and she'll see about getting somewhere closer to home to organise physiotherapy so you won't have to come back here twice week (from Kildare).
(*(physiotherapist then turned to child's parents to reiterate information to them....this is reflected in the conversation I had with child....does the child's age have an influence here in that she is older so more information is relayed to her in addition to her parents plus she is familiar with her operation as this is not her first))*
So the physiotherapist said well I'm happy for you to go home and turned to Chloe and asked her if she felt okay using the crutches. Chloe replied ya grand
*(see conversation with Chloe – I spoke to Chloe again today and asked her about using the crutches and the physiotherapist she reiterated all that the physiotherapist had said)*

# APPENDIX 26

# FIELD NOTE EXTRACTS: MY ROLE

**A Friendly Player (distraction and boredom reliever)**

Maria (10 years) was very much at ease with me and chatted along as we played a game. This proved beneficial as it took the emphasis away from direct questioning. I felt relaxed chatting with her. Even though her responses to me were brief and short she was telling me as it was and not what she thought I wanted to hear, I believe. (Field Note Extract Nov 2004)

**Researcher**

I was sitting on the end of a bed of another child's who was playing the play station. Colm (13 years) came over and sat on a stool at the side of the bed in front of me. What are you doing he asked? I replied, hanging out. He asked: are you not going to ask me questions? ((Colm expected me to ask him questions. He was at ease and relaxed talking to me and with my presence. He was happy to chat no alternative tools were needed to communicate with him)) (Field Note Extract Dec 2004)

**Company (child not alone)**

While chatting to Brian 10 years his mother arrived. She said to me, I'm glad you're with him. She said she was just thinking to herself, I hope Veronica is with him. (Field Note Extract Nov 04)

**A Researcher (blurred line between conversations and observations – contextualises)**

While, the nurse coming to take observations interrupted us it was valuable in learning what the child knew about the equipment and the language he used. It will help with setting the context for the study. (Field Note Extract Nov 04)

**A Person in my own right (children as gatekeepers)**

When sitting on Sean's bed chatting with Sean and Gary, Sean 10 years asked me more questions about what I do. They asked me questions about where I live, what car I have, where do I go (after finish on ward) and what do I really do. (Field Note Extract Nov 2004)

**An Informer (reciprocity)**

Sean and Gary asked me questions about the hospital school like what do they do there and would they be able to go. Gary asked, do they do lunch? (both laughed as Gary was fasting and thinking about food). (Field Note Extract Nov 2004)

When conversing with Colm he asked me, will I have to get my stitches out? I said: I don't know sometimes they use dissolvable ones…yours I don't know. Colm said I can't see it (wound) I don't have eyes in the back of my head. I explained his wound to him. (Field Note Extract Dec 2004)

**A Nurse Intervening (dividing line researcher versus carer)**

Should I be making beds? I should be working with children not staff (Field Note Extract Oct 2004)

I felt guilty with people running around me busy. I wondered how did they perceive me, standing around, but, I didn't want children to see me on the side of staff or as staff (Field Note Extract Nov 2004)

As I walked around a post registration student nurse said to me, in an anxious hurried and slightly raised voice, can you call one of the staff nurses for me? The student was with a 10 month old baby who had a tracheostomy. At this point, I looked at the baby, he was a bit red in the face, coughing (he was sitting in a ring on the floor). My thought was do I intervene or go get the staff nurse. From my experience, I felt the infant was okay it was just the student was not used to caring for a child with a tracheostomy and was anxious. I went to call the staff nurse who went immediately in. The staff nurse was holding another baby on her hip, which I held until she settled the other infant and reassured the student he was fine. (Field Note Extract Nov 2004)

A mum came out onto the corridor about 8.30 looking for a nurse. Mum asked a staff nurse if she was busy because she needed a hand with her daughter. I heard the staff nurse say she was busy. I had been talking to this mum and her daughter the day before,

so I asked her, can I help? *((I thought it might be an opportunity to build rapport with the girl as I had spoken with mum and this girl the day before and they seemed interested in participating but unfortunately they left the hospital daily to receive treatment and were not back until late when she was often tired))* I helped her lift her daughter out onto a commode to go to the bathroom and then back again. Mum was getting her daughter into her swimsuit to go out for the morning for physiotherapy and hydrotherapy. Mum was looking for the wheelchair. I fetched it. Next, a staff nurse arrived and said to mum "the taxi's here". Mum said; "we'll have to bring the toast with us" as her daughter was just about to tuck into her breakfast. The staff nurse said "meals on wheels". *((I couldn't help thinking if I had not helped mum this girl would not have been ready to go when the taxi arrived and I was glad I had helped however it does question the divide in my role between researcher and my commitment to help as a nurse))* (Field Note Extract Feb 2005)

**Not a Nurse**

It was now about 11 o'clock. I was sitting in an armchair beside Luke (11 years). He was handling his wound drain. I heard a big whooshing sound and asked him, was that you? At that point, Luke called out "nurse" and said to me "get the nurse quickly". I looked at him and saw a scared expression, I went to the room door and asked a nurse across the way at the nurse station if she could come into Luke for a minute "quickly" as he had stated. The staff nurse came in asking Luke "what's wrong?" Luke told her the drain had broken. She responded, oh ok, that's ok (looking at the tube) I'll fix it. (Field Note Extract Feb 2005)

**Reactivity**

One of the staff nurses opened the door at the surgical end and called another nurse from the door (shouting down the corridor). Then she ran into the ward and saw me, smiled in my direction, saying oh so unprofessional I know. The CNM was standing at the drug trolley on the corridor and she said yes so unprofessional (laughing) (Field note Extract Nov 2004)

# APPENDIX 27

# SAMPLE OF CONVERSATIONAL FIELD NOTES

**Ann (8 years)**
**Pre Op for Eye Surgery - Strabismus Repair**

**On Admission: Day 1**

When I met Ann she had just been admitted to the children's ward in the evening time. She was due to have surgery the next day. I had met her mum and she consented for me to spend time with Ann and invite Ann to take part in the project. Ann's mother had to leave on the evening on admission but before she left I met Ann and she was happy to take part and for me to spend time with her. When I went back later to see Ann she was looking out the window to see if she could see her mum's car. She told me her mum had to go to a parent teacher meeting in the school but she would be back later. She told me the guy with her mum earlier was her older brother. Ann talked extremely freely. She showed me her armband and asked me why she had it. I just looked at it and stated it was her name ((seeking information from me, was she not told why her name band was put on what was she told I wonder.))

She immediately moved on to show me a book one of doctors ((I ? whether this was a nurse)) had given to her when she came to the ward. She stated she had read it already. ((format of information – written information))

((I recognised the book, it was the preadmission book, given to children who come into the preadmission club. This was the first time I had seen a child on the ward with it. Interestingly I had asked the day before about information available on the ward for children when they came in; although there was different staff on today could this have been an influential factor in this child been given this booklet)).

Ann went on to tell me that she had met loads of doctors since she had come in/loads of doctors had come to see her since she came in. They had asked her loads of questions but also they told her about the operation and that she could not eat; only breakfast in the morning. She was now waiting to go see the doctor but her mum had to go. She had a second older brother it was his parent teacher meeting. She told me that downstairs she had to get up on the weighing scale. ((I question whether the child was calling doctors / nurses all doctors – as can be seen in next section))

See that doctor (pointed to a CNM in a blue uniform) she put on the cream.

VL: Cream.

Ann: You know the cream that numbs your arm

VL: What's it for?

Ann: Don't know I can't remember

((can't remember, understandable as her mum had stated she was excited on admission))

VL: Did she tell you?

Ann: I think so

VL: So tell me why you came into hospital?

Ann: I have to have an operation on my eye.

VL: An operation on your eye

Ann: Ya I have a lazy eye

VL: Lazy eye

Girl: It's the muscle…you see this one doesn't work (pointing to her eye). When I get my eyes tested this one is good (pointing to eye) (she was wearing glasses). The operation will make it (eye) better.

((Ann was able to relay information about why she had come in and why she needed the operation…it would make her eye better…so here doctor / operation would make her better…what does this mean?))
VL: How do you feel about having the operation?
Ann: Nervous
VL: Nervous how come?
Ann: You feel rotten after it (operation) when you wake up…and sore…but then you get better. One doctor who gave me that (pointing to her name-band) told me she had operation done on her eye and she was fine now
((was nervous about operation because of how she would after it …but she would get better…self-disclosure of nurse (as name band I would presume this was a nurse)))
VL: Do you know what they are going to do…like what do you know about the operation?
Ann: ….em ….they put you asleep I think, do they?
VL: Yes
Ann: Do they cut your eye open? My mam said they don't, do they?
((so here used word cut eye open….still had questions …she was thinking about what was going to happen…asking me….her mother had given her information about the operation))
Ann kept talking she told me she got a letter in the post last April. This was when she first heard about the operation. Then it (operation) was put off and off until now; she didn't know why. Her mam said it was because it (hospital) was too full ((information sent in post to elective admission similar to Frank 11 years))
This was Ann's first time in hospital, actually staying in, but she said it was just for two nights ((so does that mean it was okay because it wasn't for a long stay))
Ann asked me: Are nurses nice? Were you a nurse?
I said yes and she stated: I don't know I'll have to see
((asking me questions wondering what nurses are like))

**Comments/Thoughts**
Ann was extremely chatty and excited. Through her admission and night before her operation I was able to learn that she was wondering what was going to happen, she did have questions and asked me things. She was given some written information book about hospital yet did anyone go through this with her. I felt relaxed talking to her and actually stimulated by her questions and thoughts I was even thinking was she was really wondering what was going on inside her head. Ann seemed only too delighted to talk to me and was not shy at all. When chatting she was sitting up on her bed, I sat on a chair beside her bed. The TV was on above us but Ann wasn't watching it nor was she distracted by it. She didn't seem to know the difference between doctors and nurses. Had the CNM not introduced herself as a nurse? Some rituals of the admission process were apparent: weighing patients, putting on armbands, asking questions, the numbing cream. Is this labelling the child patient? Question - short stay acute/elective admissions: how do these children find out about hospital/operations?

**The next day: Day 2**

VL: Hi there how are you?

((I seem to start my chats with kids the same way HCP do?...yet in looking at responses I seem to get different response like from this girl she was telling me what was happening. Is this because she saw me differently related to the project and I had time to sit and chat/built rapport))

Ann: I'm not allowed to eat today

((food fasting seems to be a bit issue for children - a lot of children going for surgery focus on not being able to eat))

VL: You can't eat today

Ann: I have to have my operation. I had breakfast already really early, two nurses woke me, it was still dark (looked out window beside her bed). Can I get dressed? VL: Yes I'm sure you can

Ann: Pull around the curtain cause there is a boy there; I don't want him to see me

VL: Would you like to go to the bathroom?

Ann: No there is no lock on the bathroom door

VL: Okay (I pulled the curtains around her bed and waited outside as she got dressed) ((privacy, mixed rooms boys and girls))

When Ann was finished she pulled around the curtains.

Ann told me she had a book given to her by a doctor yesterday evening when she came in, she started to read out loud some of it to me. She was reading about having a sign on her bed that would say FASTING she pointed to me that she had a sign on her bed 'look I have fasting (sign) on my bed...but I didn't have my operation yet'

VL: What fasting mean?

Ann: Don't know

VL: What does the book say?

Ann: (reading from book) fasting can't eat or drink...then she kept reading on about the operation from the book.

((so similar to what she told yesterday evening that written information was given to her about operation, information was given the night before the operation this is the morning of the operation she is reading the book. What the book said related to what was happening to her, the fasting sign on her bed. Interesting she did not know what the word fasting meant and didn't relate this to not been able to eat / drink which she had informed me earlier))

Ann told me she had read the book the evening before and her brother had helped her with big words because there were some big words she didn't understand

((this was a copy of a preadmission information booklet for children. I found one copy of it on the ward - having to ask the CNM. This was the first child that I had come across that was given it. However no one read it to her and she clearly did not understand some things in it. So I question is it geared to her age? Or was it too difficult as there were words she did not know? Also should she not have gotten this information before admission? Furthermore written information needs to be backed up verbally))

Ann asked me to do her hair handing me her hairbrush and bobbin to tie up her long hair in a ponytail as I did this she asked me if I went home or stayed here last night (as I had seen her the evening before). I told her I had gone home.

Ann stated the doctors went home but nurses stayed here.

While I was talking to Ann two nurses were across from us making beds.
A ward attendant entered the room to check with one of the staff nurses who had to go the eye clinic.
The staff nurse said: Ann and (name of boy in another room).
On hearing her name Ann said to me; why is she saying my name
((listening watching to what going on around them))
Then the ward attendant came over and said: Ann, are you ready pet we're going to the eye clinic? They left.

**Comments/Thoughts**
Ann was chatty and talked at ease. During the conversation I sat on the end of Ann's bed and she moved around, she stood next to me showing me the book and had it open on the bed reading it. Some issues emerging here were about written information and children's understanding of it, backing it up with verbal information, the timing of giving information, the issue of fasting and children's understanding of what might be classed as an everyday and also possible a medical term 'fasting'.

**Later on……**
I went back to talk to Ann 8 years awaiting Strabismus repair today. Mum was there. I sat on bed next to Ann's, which was vacant and spoke to mum briefly. Mum was reading a magazine. Ann's was there also. She was sitting up on the girl's bed. Mum asked Ann again did she want to help me with more work for the project. She did and decided she'd like to draw some pictures. She told her mum I did her hair. She asked what could she draw…..I said anything about hospital. She began to draw.
She was sitting on the end of her bed with the bed table in front of her, I was sitting on a chair at the other side of the bed table, mum was on a chair beside bed reading magazine and her sister was sitting at the top of the bed eating a packet of popcorn. Her mum asked her what she was drawing……..
Ann: I'm drawing this room just what I see.
She then went onto tell me what she was drawing ((I did not have to ask she automatically told me. Ann was different to the child before who was quite as she drew. Ann chatted as she drew talking about what she was drawing))
Ann showed me her drawing saying…
This is my bed, these are the curtains (either side of bed), these are the 2 televisions (above the bed), this is a press (underneath the TVs) and this is a toilet roll (on bed table). This is an empty cot (in the corner of the room). Then in the top right corner of the page she drew some more and told me what she had drawing……a doctor (female), me (child) in bed
When I asked what she (child) was saying she replied.
Ann: well I'm not saying anything I'm asleep I'm having my operation (asleep for operation)
VL: what are you thinking?
Ann: I'm dreaming
She drew a dream bubble….and wrote that she was dreaming that …. "she's [doctor] glueing the bones in my eyes back together" (fixing)
Ann asked me: what'll she doctor do…cut my eye open?

((still wondering about what the doctor going to do the actual procedure of the operation ….no one had told her but she clearly wanted this information…))
Veronica: well what do you think the doctors thinking?
Ann: that she [doctor] has glued the bones in my eye back
(When she was writing if she couldn't spell she'd ask me to spell the words for her)

Ann asked me about her operation and what the doctors would do. Her mum also asked me some questions…like how long operation would take etc…((here both child and mother had questions about the operation they used me to seek information sometimes I answered sometimes I said I didn't know…or wasn't sure…if they hadn't asked me who would they have asked? Would they have asked anyone?))

Next, I asked her would she like to draw a picture of when she went down to see the doctor in the clinic this morning.
She drew:
A box with letters in it …letters she had to read out when the doctor was testing her eyes ((examination))
Again she spoke as she drew telling me what she was drawing
This here is (name ward attendant), she is sitting on a chair
Who is (name) I asked?
Ann: she brought me down…she helps the nurses (ward attendant)
She told me that the ward attendant just sat there she didn't say anything down in the clinic
She also drew the doctor (female).
I asked what doctor saying and doing?
Ann: the doctor saying……look at the stick ((command / request)) can you see the picture ((question closed)) ((all part of physical examination))
The child drew herself and said she was sitting on the chair, she was saying: ok I am looking at the stick ((agree doing as told))
She told me she met loads of doctors there in the clinic but she was only drawing one.
Veronica: you met loads of doctors - what all doing
Ann: well one testing my eyes reading letters and one to look at the stick ((all examination))
I asked her to tell a story about doctor coming to see her.
She said ….the doctor came to see me before my operation, she [doctor] says are you ready for the operation.
The child replies ….yes I am, I will be ok 'cause I will be asleep… ((reassured asleep))
I asked her was she happy with what doctor told her
Ann: yes I am cause there are lots of toys and lots more….she is a very nice doctor

Ann's sister talked to me, she asked me was she (Ann) shy when I met her yesterday. Ann said I'm starving but I can't eat….her sister was sitting eating popcorn annoying her, her mum told her to hurry up and finish and put in bin and stop teasing her sister who was fasting.

**Comments/Thoughts**
Ann was very jumpy, talkative and excited. I felt we had built good rapport and she trusted me, she was easy to talk to. Her mother was also very relaxed. They both still had unanswered questions about the operation. The child's responses clearly see the doctor's role as doing the operation and examination of her eyes. The child's role appears passive. She saw the ward attendant as the nurses' helper. She had to leave the ward to see the doctor down in the eye clinic.

**Next Day**
I wandered in to see Ann who had her eye surgery yesterday. She was sitting on her bed brushing her hair. She was dressed. I went over to her.... Hi there...she looked down towards the bed and said ...Hi. I noted both her eyes were very blood shot.
Ann: I had my operation....my eyes were really very sore ((unsolicited information ...pain))
VL: your eyes were really sore
Ann: the doctors and nurses told me that it wouldn't be sore but it was.....they told me I might feel sick after....my tummy...but I wasn't ....my eyes were really sore....((told won't be sore but was ....truth telling ...lack of trust in HCP))

The CNM came in with Ann's breakfast.....
CNM: now breakfast...do you want a table on your bed...((CNM reached for bed table putting it up on girls bed))..... did she get calpol this morning
Ann: Sorry
CNM....Did you get calpol?
Ann: yes
CNM left

VL: So your eyes were really sore after the operation, what did they do to help the soreness
Ann: Give me cal...I can't say it
VL: calpol ...medicine
Ann: ya
VL: Did that help?
Ann: Well not really they were still sore...they tell me not to rub them (eyes) ..but...(rubbing eyes)....silence
VL: Tell me what you remember about your operation
Ann: They gave me sleepy water...goes in body and up your body up there (pointing to head)....Mam went in with me until I went asleep ...then my sister and her went to shop....I'll show you what they put here (holding out her top to show me ECG dots on her chest)...and this (IV cannula in hand)
VL: What these for?
Ann: don't know

She asked me to do her hair for her again ...to tie it up in a ponytail as she hated it down...and she asked about my hair which was tied up was it long ...I had to take my hair down to show how long it was....((my role))

A TV programme from which the girl recognised the music came on she started to sing the tune from the programme. She couldn't really see the TV from her bed so she moved to a chair in the middle of the floor where she could see. I told her I'd come back later to see her.

**Comments/Thoughts**

Ann was clearly upset by the fact that she was sore when she was told it would not be …she stressed it was really very sore. Do HCP believe that operation would not be sore? That they would give enough pain relief that it wouldn't be sore? Or do they tell children wouldn't be sore as reassurance or protect them from distress before the operation? However by not telling the truth child may loss trust in HCP especially for future endeavours? Is there a relationship between truth telling and children's age / developmental level - like re what should tell?

I found Ann really easy to talk and she was definitely telling it as it was / is. I had to ask very few questions as she gave unsolicited information. Re the issue also of her showing me the ECG dots / IVC…see what did to me…things done to her without her knowing she didn't know what these were for…is this right? She was not given information before the operation….then woke up with these things and didn't know what they were for?

# APPENDIX 28

## FIELD NOTE EXTRACTS
## IMPORTANCE OF BUILDING RAPPORT

**Importance of Rapport Building**

When I arrived back at 14.00 Jodie (9 years) was waiting for me, sloughed in her chair. I confirmed she was happy to help me with the project. She nodded her head, indicating yes. I started by telling her about the project again to ensure she was clear about it despite already having received consent previously (from both Jodie and her mum). Then I delved in and started to talk about all the different people she had meet in hospital. She responded by saying *my mam, auntie, brother*. I then asked about the people who work in hospital and she told me *doctors and nurses*. I asked her about whether the doctors and nurses talk to her. She shrugged her shoulders. I asked why she had come into hospital. She told me to *get my appendix out*. What's that, appendix? I asked. *Don't know* she said. I asked did anyone tell her about your operation. She said, *no* (pause) *they put you asleep. ((I clearly realised this was not the way to go and not a good way to get information from Jodie. I was anxious about 'gathering' and 'getting data'. I just jumped in and starting asking questions. However, I should have known from some observations of been on the ward Jodie generally interacted little with nurses and tended to look sad and bored))* Once I realised this was not the way to go I asked Jodie would she like to play a game. She nodded yes then asked *what game?* I asked her what games she liked to play. She said *monopoly*. I found one of the play volunteers out on the corridor and asked if she could get us game. The play staff followed me back to the girl and sat on the bed next to her saying, so Jodie you would like game monopoly. No problem ill get that for you (she left). I sat on the bed beside Jodie waiting. We sat in silence, the TV was on and we watched that. At one stage, Jodie spoke saying *it's taking so long.* What's taking so long I asked. *For her to get the game* Jodie responded. I said I think she had to go to Hong Kong to get it. Jodie smiled. When the play volunteer returned, Jodie said to her *did you go to Mars.* The play volunteer laughed and said *ya I nearly did.* She then went on to say I got you junior monopoly, I don't know the rules of the game and there are no instructions but it's probably the same as the older monopoly game. *((The importance of researcher using humour and the importance of humour to children is illustrated throughout this rapport building exercise. It is interesting children also value humour in their interactions with staff)).* We played the monopoly game and had some good fun. Jodie was now laughing and messing, and chatted away to me. She asked me questions

about myself like where did I live. Alongside playing Jodie said to me, *I want to get out of here...this room and hospital* (she wanted to go home). I probed further once Jodie gave me this unsolicited information asking *how come?* She said she was *bored and wanted to have fun....and hated being sick.* (Field Note Extract Nov 2004)

**Thoughts**

Today I saw that research with children is different from research with adults. Research with children needs to be flexible. I was worried about being able to argue the validity and reliability of my research findings. From yesterday's rapport building and today's chats I feel collecting data in this natural hospital context and building this rapport with the child in addition to informality, flexibility and recognising the individuality of children by acknowledging their different developmental levels are extremely important. One thing is for sure in doing research with children needs time. (Field Note Extract Nov 2004)

# APPENDIX 29

# SAMPLE OF FIELD NOTE CONVERSATIONS THAT TOOK PLACE ALONGSIDE STICK-A-STAR QUIZ

**Sample 1: Sinead 9 years: Appendectomy**

Q1 How often does the doctor talk to you?
Sinead: A little (2stars)
VL: How often would he have to come to see you to get more stars, say 4?
Sinead: Maybe everyday
VL: So the doctor doesn't come to see you everyday
Sinead: No he came the day before the operation ….to say I was having my appendix out and then yesterday…I think yesterday …yes...to tell me I could eat.

Q2 How much information does the doctor give you?
VL: Do you understand what I mean when I say information?
Sinead: Yes a little (2 stars)
VL: Can you tell me what information he gave you?
Sinead: He told me that I was going to have my appendix out and that I couldn't eat or drink and then yesterday that I could eat at 3o'clock.
VL: What else would he have to tell you to get 4 stars, do you think?
Sinead: if he told me about the operation and what he was going to do….and what was going to happen.
VL: OK, so you'd like to have known more about the operation and what was going to happen in theatre.
Sinead: Ya nodding (yes)
((Here Sinead reveals the type and what information she was given and also what she was not given but would also like to know – insufficient information))

Q3 How much did you understand what the doctor was saying?
Sinead: A lot (4 stars)
VL: So you understood everything the doctor was saying
Sinead: Yes

Q4: How much did the doctor allow you to speak/have your say?
Sinead: None (1 star)
VL: How could he have given you some say…like to get more stars?
Sinead: If he asked me if I was scared or worried about the operation, or if I wanted to ask anything.
((Here Sinead again identifies her agenda as being important in that she wasn't asked if she wanted to ask questions which would have allowed her to ask about what she wanted to know. Also Sinead has revealed that her emotional needs were unmet))

Q5 How much did the doctor listen to you?
Sinead: None (1 star)
VL: Can you give me an example of when the doctor didn't listen?
Sinead: Like he told me, I had to have my appendix out then just walked away.
((the *just walked away* sticks out here – what does this mean?))

Q6 How much/often does the nurse talk to you?

Sinead: Loads (4 stars)
VL: Loads…. like how many times
Sinead: Loads of times every day like every half hour
VL: and what kind of things do talk about
Sinead: they ask me how I am…and do I need anything…am I hungry
((staff ask questions, here again appears *asking how one is*))

Q7 How much information does the nurse give you?
Sinead: A little (2 stars)
VL: A little can you tell me what information the nurse does give you
Sinead: On of them told me what time I was going for my operation at……and when I could eat and drink
VL: What would get them (nurses) 4 stars
Sinead: Like if they told you what things you could eat or drink…..they only told me that I could eat and drink
VL: Did they tell you about what was going to happen when you went for your operation
Sinead: No
VL: What about these (pointing to IV cannulas) …what these for?
Sinead: I got one in casualty and the other one in theatre….I had it when I woke up after my operation
VL: Did they tell you what it was for?
Sinead: No
((identified in this passage is a lack of information given to Sinead about her operation apart from being told she was going to have an operation she was told no more about what was going to happen, she woke up with IV and while knew it was for a drip no one told her. Does this matter? Do children want to know or need to know these things?))

Q8 How much did you understand what the nurse was saying?
Sinead: em…..well I didn't understand what the drip was for……..and I didn't know why I couldn't eat or drink….. I just knew I couldn't eat or drink but didn't know why.

Q9 How much did the nurse allow you to speak / have your say?
Sinead: Some (3 stars)
VL: Can you give me an example
Sinead: Like they'd ask me how I am

Q10 How much do you think the nurse listened to you?
Sinead: A lot (4 stars)
VL: Can you give me an example
Sinead: When she asks me how I am she listens to what I have to say

**Thoughts**
So, what different sorts of information are children given and would you like to be given? Is getting information important to children, why? Why was the girl scared about the operation was it something in particular that made her scared? If she knew more would she have been less scared? When children are given no say – what do they think about

this? Do they want a say? Is it right that given no say? How could they be given more of a say?

*Recorded by Veronica Lambert Jan 2005*

**Sample 2: Rory 12 years: Fractured Pelvis**

In this particular instance, Rory did not physically use stars to stick onto the quiz but we used as a forum for discussion to guide our conversation. My main reason for using this was to help me clarify some of the things we had talked about earlier.

Q1 How often does the doctor talk to you?
Rory responded 3 stars (some) and stated that the orthopaedic doctors would come every two days, they came more at the start when he came in first, like every day, to tell him what was wrong.

Q2 How much information does the doctor give you?
Rory responded 3 stars (some) stating that the doctors tell you some information.
I asked why he gave 3 stars for some information.
He replied because they [doctors] tell your mam more information.
I asked specifically about what information Rory was given.
Rory told me he was informed about what wrong with him, about going home – they [doctors] said wait and see - about how long he'd be in. First, they said a week then after a week, they say another week.

Q3 In relation to this next question, how much of what the doctor says do you understand? Rory stated 3 stars (some) We had talked about this earlier and what he said was repetition of what he said earlier in relation to his interpretation and the words the staff used such as pelvis etc. (refer to previous field notes as Rory repeated the same issues)

Q4 How much does the doctor allow you to speak / have your say?
Rory allocated the doctor 4 stars (a lot) here stating he felt he was given lots of say because he got to ask questions about going home and about what they are going to do.

Q5 How much does the doctor listen to you?
Rory allocated the doctor 4 stars (a lot) because he felt the doctor listened to him a lot. This was evident he said by the fact that doctor stopped talking like they [doctors] don't keep talking they listen to him when he is talking and they give him an answer they don't say they don't know they say it might be this or this.

Q6 How much does the nurse talk to you?
Rory felt the nurses talked to him a lot so they allocated 4 stars. Rory went on to tell me that the nurses ask him different things like how you are keeping? Are you sore? and ask him about his music ((personal things))

Q7 How much information does the nurse give you?
Here, Rory allocated 2 stars for a little because he felt that nurses don't really give information. He said they [nurses] leave it up to the doctor.
I asked him what he thought about this.
Rory said - good because they (nurses) might get it wrong. The doctor knows more and he should tell you. He went onto say, the nurses tell you about things to do though like play station and that the schoolteacher comes to you.
((Rory sees the doctor as the main information giver and thinks that the doctor should be the main information giver. Nurses might not know the information. He makes a distinction between the type of information doctors and nurses give.))

Q8 How much of what the nurse tells you, do you understand?
Here Rory said 3 stars (some) stating that the same as doctors really there are some words nurses use they don't understand.

Q9 How much does the nurse allow you to speak / have your say?
Rory stated 4 stars the nurses give him lots of say. When I asked him for an example or if he tell about when he was given a say, he stated that he got his say when he got to ask when is dinner?

Q10 How much does the nurse listen to you?
Rory also allocated 4 stars to nurses for listening to him lots. He went on to say nurses listen to what he has to ask and answer his questions.

*Recorded by Veronica Lambert Feb 2005*

# APPENDIX 30

# STRENGTHS AND WEAKNESSES OF DATA COLLECTION METHODS

| Method | Strengths | Weaknesses |
|---|---|---|
| **Informal Conversations** | Free and natural discussion<br>Child's unique perspective<br>Avoids rigid question answer<br>Spontaneous in natural setting | Bored with verbal conversation<br>Reluctant to chat<br>Limited in-depth responses<br>Confidentiality issues |
| **Stick-a-Star Quiz** | Motivation & Attention<br>Communication<br>Choice & Control<br>Recognise individual interests<br>Provide structural guidance<br>Reduces unequal relations<br>Removes focus on researcher | Limited in-depth data<br>Need to explore issues raised<br>Context difficulties: interruptions/time<br>Confidentiality<br>Ownership issues<br>Interpretation concerns |
| **Draw & Write** | Enhances participation<br>Expression of child's views<br>Not dependent on language<br>Enjoyable, fun, relaxing<br>Reduces anxiety<br>Assists rapport building | Requires knowledge & skill<br>Draw what is easy to depict<br>Abstract concepts taxing<br>Confidentiality & ownership<br>Interpretation concerns |
| **Observations** | Examine actual behaviour in its particular context<br>Assist rapport building | Risk losing the voice of the child<br>Observer effect |

# APPENDIX 31

## SAMPLE OF PERSONAL/METHODOLOGICAL THOUGHTS (MEMOS)

**Self Doubt (Inexperience, lack of knowledge, being challenged)**

I am not sure what I am supposed to be looking for, or looking at.

As communication is an abstract concept it is difficult to chat about it without asking direct questions, but I seem to be asking children predominantly about their information needs. Perhaps this is not surprising that I am focusing too much on information, as often communication is discussed purely in terms of information but it encompasses far more than this.

I am questioning my ability to collect data and the data I am collecting is it any good? My field notes seem so basic. How can I get more in-depth data from children?

Yesterday, I was upset! Any self-doubt I had was made worse. I felt humiliated, embarrassed and a sense of failure and loss. Is all the fieldwork I have done to date useless, or some of it anyway? I feel a tension between my own beliefs and the views of the more experienced others. Does that mean they are right? I feel confused now, and perhaps slightly (or greatly) frustrated. Time wasted! It's not just about me, what about the children? If at this stage, I have to start to revise and 'cut' my sample, how can I exclude children who agreed to take part? This would make me feel guilty like betraying their trust. So, what exactly is the sample in ethnographic research? And more specifically in my research!

I think of the difficulties I'm having – trying to stay close to the voice of the child? I'm afraid to move beyond the data because it's about the voice of the child, isn't it? Once again I face an internal dilemma, do I have to let go of the voice of the child to move beyond the data. Time to send more e-mails!

Overcoming one hurdle (after another) I am faced with yet another. I feel slumped. What's going on? What is it [data] saying? So many files and folders, I can't seem to put any organisation on it, it's disjointed, underdeveloped and I can't seem to make sense of

it. The most frustrating part is coming and going from it, each time I leave it and come back to it, it's like beginning again. It seemed easy in theory – codes, categorises – properties – dimensions - themes, but not in practice?

Another challenge after meeting John, am I not slurring or blurring here between ethnography and grounded theory, because grounded theory focuses on social processes and ethnographies about culture, that was his perspective. I felt a sense of panic and quickly set about questioning a number of people on this in relation to grounded theory. Yes, they agreed grounded theory looks at processes. Could it be? If I was would it matter? Need to return to ethnography literature to explore this further.

**Reassurance – Gaining Confidence (enhanced through knowledge - built through literature engagement and interactions with others)**

I feel a bit more reassured after these e-mails for these appear to be similar challenges others have faced. There doesn't seem to be any concrete solutions. It seems to be learning by doing.

Today, I felt a sense of relief, David seemed to understand where I was coming from and the challenges I faced. I was hugely appreciative of the time he spent with me, in the context of his own home and family.

I was very nervous beforehand and spent a lot of time preparing and put a lot of effort into the presentation. But it all paid off, the feedback was great. I feel amazed, as others did say also, how far I have come - but still far to go. But it definitely adds to my motivation and enhances my confidence. I feel a new drive to move forward.

Once again, it proved valuable to e-mail a few people. (I wonder what do people think when they receive these e-mails from poor struggling students, I am always surprised by the immediacy of responses and valuable information offered, which seems so much more practical (and personal) than many textbooks).

After delving back into ethnography literature, I can now defend the previous critique in relation slurring or blurring and the issue of culture and social processes. There are different interpretations within ethnography about the levels of culture and about social behaviours and processes, Debate this within my methodology.

I felt so reassured after attending Martyn Hammersley workshop, especially his comment about the complexity and flexible nature of data analysis, the to and fro movement, and more especially when I asked the question; how can this be displayed on paper? (I was thinking here of me personally as I was grappling with giving a systematic step-by-step account of the process of data analysis). His response was it is impossible.

**Participatory Activities: A Focus and Stimulus for chatting**

They [activities - drawing] were good in that they gave him something to focus on rather than just sitting chatting and proved a good stimulus for talking (Field Note Extract Nov 04)

**Observations: Lack of Space**

It is difficult there is no space in the rooms, especially down the medical side. Where do I go to observe….if I'm observing and trying to take in the ward atmosphere and context while playing with the children, then I can't completely concentrate on observing. It is difficult to observe while doing something else; you miss things. (Field Note Extract Dec 04)

**Conversations: Thinking on Feet and Remembering**

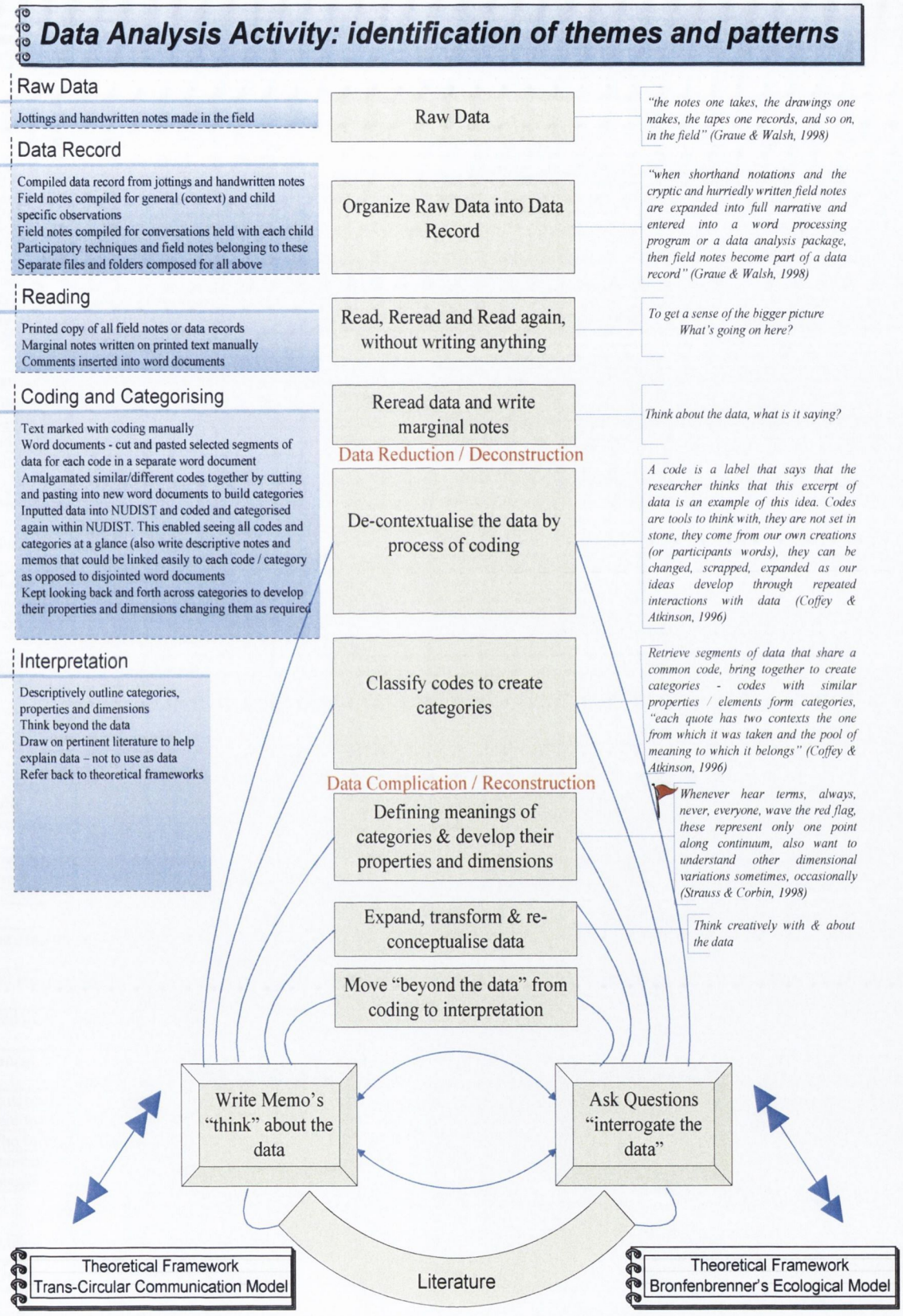
It's difficult to think on feet about the next question to ask and explore what children are saying further especially when trying to remember what they say (because I'm not tape recording) (Field Note Extract Dec 04)

**Building Rapport: More Time**

I needed more time to build rapport with Holly and spend more time with her prior to soliciting information. Unfortunately she was discharged the next morning so I never got to follow her up, however some valuable issues emerged as bracketed above to follow up on (Field Note Extract Dec 04)

# APPENDIX 32

# DATA ANALYSIS ACTIVITY


Data Analysis Activity: identification of themes and patterns
Raw Data
Jottings and handwritten notes made in the field
Data Record
Compiled data record from jottings and handwritten notes
Field notes compiled for general (context) and child specific observations
Field notes compiled for conversations held with each child
Participatory techniques and field notes belonging to these
Separate files and folders composed for all above
Reading
Printed copy of all field notes or data records
Marginal notes written on printed text manually
Comments inserted into word documents
Coding and Categorising
Text marked with coding manually
Word documents - cut and pasted selected segments of data for each code in a separate word document
Amalgamated similar/different codes together by cutting and pasting into new word documents to build categories
Inputted data into NUDIST and coded and categorised again within NUDIST. This enabled seeing all codes and categories at a glance (also write descriptive notes and memos that could be linked easily to each code / category as opposed to disjointed word documents
Kept looking back and forth across categories to develop their properties and dimensions changing them as required
Interpretation
Descriptively outline categories, properties and dimensions
Think beyond the data
Draw on pertinent literature to help explain data – not to use as data
Refer back to theoretical frameworks
Raw Data
"the notes one takes, the drawings one makes, the tapes one records, and so on, in the field" (Graue & Walsh, 1998)
Organize Raw Data into Data Record
"when shorthand notations and the cryptic and hurriedly written field notes are expanded into full narrative and entered into a word processing program or a data analysis package, then field notes become part of a data record" (Graue & Walsh, 1998)
Read, Reread and Read again, without writing anything
To get a sense of the bigger picture
What's going on here?
Reread data and write marginal notes
Think about the data, what is it saying?
Data Reduction / Deconstruction
De-contextualise the data by process of coding
A code is a label that says that the researcher thinks that this excerpt of data is an example of this idea. Codes are tools to think with, they are not set in stone, they come from our own creations (or participants words), they can be changed, scrapped, expanded as our ideas develop through repeated interactions with data (Coffey & Atkinson, 1996)
Classify codes to create categories
Retrieve segments of data that share a common code, bring together to create categories - codes with similar properties / elements form categories, "each quote has two contexts the one from which it was taken and the pool of meaning to which it belongs" (Coffey & Atkinson, 1996)
Data Complication / Reconstruction
Defining meanings of categories & develop their properties and dimensions
Whenever hear terms, always, never, everyone, wave the red flag, these represent only one point along continuum, also want to understand other dimensional variations sometimes, occasionally (Strauss & Corbin, 1998)
Expand, transform & re-conceptualise data
Think creatively with & about the data
Move "beyond the data" from coding to interpretation
Write Memo's "think" about the data
Ask Questions "interrogate the data"
Literature
Theoretical Framework
Trans-Circular Communication Model
Theoretical Framework
Bronfenbrenner's Ecological Model

# APPENDIX 33

# INITIAL CODING

| | | | | |
|---|---|---|---|---|
| Allocation of turn to child (by hcp) | Allocation of turn to parent (by hcp) | Age (dev) appropriate explanations | Ask for anything get it straight away | Ask - they forget have to remind them |
| Allocation of turn to child by parent | Ask me what do I want | Asked opinion | Aids to understanding | Asking parents questions |
| Ask parents what it means | Always in good form | Busy staff | Busy children | Better – make/get better |
| Being nice | Big mad words | Bored | Change of direction in conversation | Children initiating interactions |
| Children asking me questions | Changing topic | Child asking parent questions | Check you ('obs') | Converging to medical terms (child) |
| Child asking questions | Child butting in | Converse directed to parent | Child not ask questions | Child respond (or not) |
| Certainly not 'horrible' | Consultant listens | 'can put this on your finger' | Children's limited knowledge | Closed questioning |
| Don't tell me lies (I'm older) | Don't know what they are saying | Didn't understand some words | Different language | Didn't get a chance to say anything |
| Day and night nurses | Distraction | Don't worry | Dishonest | Difficult to get attention |
| Different nurses everyday | Doctor telling/informing child | Doctor asking child questions | Didn't introduce self | Don't understand words |
| Don't understand medical terms | Easy to talk to | Explaining | Exploring child's view | Encouraging child to speak |
| Examine you | Educating | Friendly staff | Frequency of contact | Funny 'mad' |
| Feelings | Genuine | Getting better | Given a say | Getting to know them |
| Getting staffs attention | Given opportunity to ask questions | Have a laugh | Having fun | Home |
| How are you feeling? | Humour | Honesty | Its for your good | Inventing child friendly words (child) |
| Information source | I'd ask if I don't know | I'm not that young that I don't know | I know all the words from school | Interruption |
| Informed child (staff) | Its to make you better | Junior doctors don't listen | Just want to get better | Just walked away |
| Just woke up with it | Joke around | Knowing who's who | Knowing from home | Knowing from TV |
| Knowing staffs names | Knowing from school | Lack of exploration of emotional needs | Loads of different staff | Learning from each other |
| Listened to | Messing/teasing | Modes of communication | Make you better | Noise |
| Not nice staff | Not exploring children's concerns | Not being informed/told | Not given a say | Not too young to understand |
| Not knowing who's who | Not explaining | Nice staff | Nurse asking child | Nurse telling child |
| Not wanting to know | Nurses change | Not asked opinion | Not listened to | Nurses don't really give information |
| Not stuck up like down to earth | Nurses understand doctors | Nurses break down what doctor saying | Orienting | Older told more |
| Overhear / eavesdrop | Open ended questions | Observe what's happening | Play | Parent explain simpler |
| Prior experience | Physical needs | Psychological needs | Parent informs child | Parent butting in |
| Parent presence | Parent don't understand | Repetition of information | She's 'sound' - genuine | Social chat |
| Students take time out | Series of questioning | Should use smaller / simpler words | Should explain what words mean | Smiled |
| Sometimes understands | Sometimes want to know | Students/drs/staff don't know about | Same nurses some days | Type of information |
| Tell me as well as parents | Training nurses are better | Talking about child in his/her presence | Task focused | Talk to you all the time 'when come in' |
| Told more as get older | TV influence | Things children want to know | Tell my parent not me | Truthful |
| Timing of information | Told because I asked | Told everything wanted to know | They don't ask me if I understand | Talking a different language |
| Understood what they were saying | Understood when used English / ordinary terms | Used easy words | Understood because they explained it | Worries |
| Who informs | Wanting to know more | Weird words | Where information given | Wanting to know |
| You can never tell me enough | Younger child would not understand | Younger tell parents more | You'll be asleep | Your grand |

# APPENDIX 34

# ATTEMPTS TO GROUP SIMILAR/DISSIMILAR CODES INTO CATEGORIES

| Category | Thoughts | Grouping Codes |
|---|---|---|
| Communicating directly with parent not child | Staff communicating with parent not the child but the child listens in the background, overhears what parent and staff are talking about. They are talking about the child as if he/she is not there. Child doesn't understand. | Overhearing/eavesdropping<br>Talking about child in his/her presence<br>Conversation directed to parent<br>Tell my parent not me<br>Allocation of turn to parent (by HCP) |
| Rapport | I have clustered all these together as I see similarities across a number of things here. A lot of these relate to personal qualities, being nice, being honest and genuine. Also the use of humour and having a laugh/fun, knowing the staff. Are these rapport building strategies and the relationship building aspect of communication. | Being nice / nice staff - Not nice staff<br>Dishonest -Honesty<br>Truthful<br>Didn't introduce self<br>Easy to talk to<br>Friendly staff<br>Funny (mad)<br>Genuine / Sound staff / not stuck up / down to earth<br>Getting to know them<br>Humour<br>Joke around / have a laugh / have fun<br>Knowing staff names<br>Knowing who's who / Not knowing who's who<br>Messing / teasing<br>Social chat<br>Smiled<br>Certainly not horrible<br>Always in good form |
| Understanding | Here I bring all codes together related to understanding<br>Instances children understanding, not understanding, staff and parents helping understanding, what helps understanding (e.g. simple terms) and why don't understand (e.g. complex medical terms, age). Also staff not checking children's understanding fits here.<br><br><u>Also see here…..</u><br>Nurse as mediator / link (to help understanding)<br>Parent as mediator / link (to help understanding)<br>What's relevance of 'parent don't understand either'?<br>Interesting here is as well children themselves using medical terminology but not necessarily understanding it and inventing words for things they didn't know names. | Language used by health professionals<br>Big mad words<br>Aids to understanding<br>Don't understand words / don't know what they are saying<br>Should use smaller / simpler words<br>Sometimes understand<br>Talking a different language<br>Used easy words<br>Understood because they explained it<br>Understand what they are saying<br>Understand when used English/ordinary terms<br>Parent don't understand either<br>Parent explain simpler nurses break down what doctor saying<br>Nurses understand doctors<br>Weird words<br>Ask parent what it means<br>Inventing own child friendly words<br>Converging to medical terminology<br>Younger child would not understand<br>Not too young to understand<br>Difficult language<br>Modes of communication<br>I'd ask if I don't know<br>They don't ask me if I understand |

| | | Should explain what words mean |
|---|---|---|
| Information | Differences here in relation to type, amount of information and who gives information. So need to look across all these issues. Generally appears some want info/some given info, some don't want info/not given info and some given info but it was insufficient (others given enough).<br><br><u>Also see here….</u><br>Nurse as mediator / link (to inform)<br>Parent as mediator / link (to inform)<br>Issue here in relation to difference between senior staff and junior staff<br>What does 'told because I asked' mean? Child informed because asked for information. | Doctor telling/informing child<br>Nurse telling/informing child<br>Explaining/not explaining<br>Educating<br>Orienting<br>Information source<br>Informed child (staff)<br>Not wanting to know<br>Sometimes want to know<br>Wanting to know<br>Wanting to know more<br>You can't tell me enough<br>Just work up with it<br>Not being informed / told<br>Repetition of information<br>Timing of information<br>Where information given<br>Student's won't know<br>Tell me as well as parent<br>Told because I asked<br>Parent informing child<br>Younger tell parent more<br>Told more as get older<br>Modes of communication<br>Things children want to know<br>Told everything wanted to know<br>Who informs<br>Nurses don't really give information<br>Type of information |
| Children questioning<br><br>Seeking Information | Here I have clustered children asking question from staff, parents and even myself. But I think this relates also to the information category above as is this not children seeking information, whereas above is very much children being informed. Some children didn't ask questions.<br><br>I have grouped three other codes here also but I'm not sure if they fit, that is opportunity to ask questions (given to child), child butting in and child initiating interactions, need to look more closely at what these mean? | Child asking questions<br>Child asking parent questions<br>Child wouldn't/not ask questions<br>Children asking me questions<br>I'd ask if I don't know<br>Given opportunity to ask questions<br>Child butted in<br>Child initiating interactions |
| Exploration | Here as opposed to informing the staff are asking children questions – exploring or not exploring. There are lots of different things within here that I need to look more closely at, especially the type of questioning, perhaps exploring concepts within communication textbooks might help with this. | Doctor asking child questions<br>Exploring child's view<br>Not exploring child's concerns<br>Open ended questions<br>How are you feeling?<br>Closed ended questions<br>Asked opinion / not asked opinion<br>Encouraging child to speak<br>Given a say / not given a say<br>Didn't get a chance to say anything<br>Ask me what do I want |

| | | |
|---|---|---|
| | | Nurse asking child<br>Series of questioning<br>Allocation of turn to child (by HCP) |
| ? subcategory of exploration | I have grouped these issues together and feel perhaps sub-category of exploration as what was evident is that there was limited exploration of children's emotional needs. Children often relayed how they were feeling at different times to me. | Feelings<br>Worries<br>Psychological needs<br>Lack of exploration of emotional needs<br>Not exploring child's concerns |
| Parents<br><br>? Using parents<br>? Parent as mediator | Here I section parents out to see if this a category in itself, while overlaps with understanding and information sections above it could be a category on its own | Parent informs child<br>Parent explain simpler<br>Ask parent what it means<br>Child asking parent questions<br>Parent butting in<br>Parent presence<br>Allocation of turn to child by parent |
| ? linked to Rapport or impacting on Information | These codes relate to the availability and accessability of staff, in addition to continuous / discontinuous care. Would this issue of continuity and discontinuous care link with rapport and relationship building? Not sure about the availability and accessability of staff? Look across these again to see if linkage to communication issues (e.g. impact on information)? | Getting staffs attention<br>Difficult to get attention<br>Different nurses everyday<br>Frequency of contact<br>Loads of different staff<br>Nurses change<br>Day and night nurses<br>Same nurses some days |
| Listening | I sit listening and not listening on it's own at the minute as I'm not sure what it directly links to. | Listened to<br>Not listened to<br>Just walked away<br>Junior drs don't listen<br>Consultant listens |
| Age differences | I have grouped anything related to age here although they appear under other clusters as well but I need to look across ages as there appears to be some indication that there were differences across ages. | Age appropriate explanations<br>Not too young to understand<br>Younger child would not understand<br>Younger tell parents more<br>Told more as get older<br>Don't tell me lies (I'm older) |
| Context (of where communication takes place/impinging factors?) | I have grouped these codes together as they essentially portray the task focused and physical aspect of care that children relayed when they talked about health professionals. These tasks related to how children talked about the business of health professionals. Are these factors that impinge / hinder the process of communication? What does this busyness and task focused care mean in relation to communication? | Check you ('obs')<br>Physical needs<br>Examine you<br>Closed questioning<br>Busy staff<br>Can put this on finger<br>Talk to you all time when come in<br>Task focused<br>Series of questioning<br>Ask for something they forget have to remind them<br>Ask for anything get it straight away |
| Environment (internal and external)<br><br>Links to | I think classify these as internal and external environmental influences. For instance children were able to understand because they knew words from school, they had knowledge from previous | Knowing from home<br>Knowing from TV<br>TV influence<br>Knowing from school<br>Prior experience health service |

| | | |
|---|---|---|
| information / children's knowledge | experience at home of family illness and TV programmes (external environment). Also children watched what was going on around them on the ward and talked to other child patients (internal environment). | Learning from each other<br>Observing what going on around them<br>Interruption<br>Noise<br>Distraction<br>Children's limited knowledge |
| Occupied Children | These cluster of codes really relate to what children were doing. They were occupied playing and when they were not they said they were bored. They wanted to be having fun (despite being sick). | Busy children<br>Play<br>Bored<br>Having fun |
| | What do these mean?<br>*((after exploration of literature called this premature reassurance))* | Its for your good<br>Don't worry<br>You'll be asleep<br>Your grand |
| | Getting better appeared in my writing in different formats look at these what do they mean?<br>*(( after exploration of literature called this optimistic assertion))* | Getting better<br>Home<br>Just want to get better<br>Its to make you better |

# APPENDIX 35

# EARLY ANALYTIC MEMOS

## Information (Provision and Needs)

From children telling me that they were informed - they were able to relay to me the information they were told - but also the information they wanted to be told. Children's knowledge was evident in their responses - what they were able to tell me. Knowledge relates to the level of children's knowing e.g. knowing word pelvis or word fracture. It is about knowledge acquisition and where do we acquire knowledge from (where learn from) our experiences, school, parents, peers, grapevine. Children are always learning and acquiring new knowledge (does this link to Piaget's accommodation and assimilation theory).

## Amount of Information

Colm relayed that the doctor told him about the operation risks, which he was able to relay to me and in doing so he used some medical terms. This is a form of convergence to medical language. Perhaps Colm attempted to show me his level of knowledge. He was happy with what he was told and said one could never tell him enough, so he was a type of person who liked a lot of information. Is there other children who would not like so much information? To be honest when he started mentioning risks I was a bit taken back especially when he mentioned going blind or his hearing getting worse. Other children might not take too favourably to hearing this information, or would they?

## Need for Information

Colm then asked me questions – he was using me to seek information about his stitches. This suggests children do have questions and need someone to ask. While they may be provided with information it may not necessarily be enough or the information they want. Although also, perhaps they are provided with information before the operation (as Colm here talked about being given extensive information in relation to risks and was able to relay this to me), but given no information after his operation.

## Understanding and Informing

Although health professionals may inform children directly (child at the forefront) when children did not understand the information they were given they are not really at the

forefront because they still did not know (overshadowed by language / terminology). In some cases children ask their parents to tell them in easier words / to explain to them (making presence known) or the nurse might break down what the doctor has said for them (bringing to forefront). This highlights that need more than one thing to be included / involved, not just being informed but being informed in an age / developmental appropriate way using language that is easy to comprehend.

### Information: Different Dimensions

So there are;

- Instances of not being informed / communicated with at all (overshadowed)
- Instances of being informed but not understanding (also overshadowed)
- Instances of being informed and understanding (at forefront)
- Also instances of when children didn't understand or when weren't informed they asked questions or sought understanding through parent (making presence known)
- Finally some did not care / want information e.t.c (happy to be in background / on side line)

### Age Difference and Informing

Is it younger children that are mostly overshadowed? They are not involved at all, they only refer to staff as communicating directly with their parents. Thus, they want some inclusion (as well as their parent). Whereas, older children are communicated with, to some extent, but so also are their parents, which they do not mind just as long as they are involved as well. It is not about communicating with the child and ignoring/excluding the parent. It is about including everyone. When children are not involved then they try to make their presence known by asking parents/nurses to explain in simpler terms or they ask questions or butt in - children used a variety of strategies to attempt to include themselves. Is there a difference here in terms of children's age? Are younger or older children more inclined to butt in and ask questions?

# APPENDIX 36

# ANALYTIC MEMOS:
# WHAT IS NOT SURPRISING AND WHAT IS MISSING?

While it is easy to overlook what is not surprising which was play for children in hospital, it was also helpful to consider what was not there. In doing this as will be seen in extracts below, I started to thing about play slightly differently.

### Play: Both Present and Absent

I suppose we equate play and its emergence as being important for children in hospital, thus I was *not surprised* in relation to children wanting to play and being bored if not. I was aware from reading the literature of the value play can be in assisting communication with younger children. Indeed, there has been much talk of the use of therapeutic play in hospitals especially as part of play specialist role. I don't remember this been included in the curriculum when I undertook my children's training. I remember learning the functions and benefits of play and the importance of it for hospitalised children but how to use play as a practical tool was never part of the programme. Thus, I don't know why I was *initially surprised* that I was not seeing play being drawn upon by nurses to communicate with young children. This is an example of something that I noted to be absent. It wasn't there in my field notes. Yes, there was play but not as a communication tool, rather it was a distraction, an entertainer not a therapeutic tool.

### Play: Impact on Communication

Previously I noted the absence of play as therapeutic communicator, but strongly present in the children's ward as occupational tools to keep children busy. Now I started to think about play in a few different ways. One what is the impact of children's occupational play on the communication process that took place between children and health professionals. For instance, I talk of the busyness of health professionals, which children frequently highlighted and my observational field notes demonstrated the continuous movements of staff. I notice the activity of children and their busyness. It appears to be two way. What does this mean for the communication process? The second thing I notice is technology as play. X-box, play station etc I need to go back to this and reflect on where this sits and how it relates to communication if at all. Is there any literature on this?

# APPENDIX 37

# ANALYTIC MEMOS: RE-CATEGORISATION

I have chosen these three extracts as examples as they clearly show concept re-categorisation.

**How are you feeling? Rhetorical Open-Ended Question**

I noticed this as repeatedly appearing across conversations with children and through observations of children interaction with health professionals. I didn't pay much attention to this at the outside, although I did code it. I categorised it as an open-ended question for at face value it explores openly the child's opinion of how they are feeling. However, now having looked at it more closely I question this assumption. Essentially, it is an open-ended question, but it certainly is not an *affective* question to explore openly how children are *'feelings'*. I revisited my original notes and became aware of how explicitly / frequently this appeared within my field notes, thus I had to re-examine it and ask the question 'what does it mean?' On deeper exploration, it was not used as an open-ended question, for children's response to this question was fine or nothing at all. Indeed, sometimes they did not get a chance to response because it was followed immediately by another question or statement. I searched the communication literature and came up with – rhetorical open-ended question – because a response is not expected. In our everyday use of it we use it as an opener or welcomer. Now I started to view it negatively because it didn't really serve a purpose in actual fact it blocked children's expression of their feelings no explored them. Faulkner (1998) referred to this as social superficial communication.

**How are you feeling? Demonstrating Presence**

Here I return to the question *how are you feeling?* Previously I had categorised this as a rhetorical open-ended question under 'blocking'. However, continuously working with the categories and returning to my original field notes and reflecting back on the children's ward, I began to consider what this question meant again in terms of how I was seeing it and perhaps how children saw it. In reviewing children's conversations and perhaps what struck me most was when Holly wrote on her drawing what the nurse was saying that is she was asking her how she was? Indeed, often when children talked about nurses talking to them and coming in to them and giving them a say, asking them how

they were was an important part in this. I looked at this from a different angle and actually re-categorise this *how are you feeling* question as demonstrating presence. However, I'm not sure where this sits in relation to other categories now. Search some literature.

**Personal Experience**

It was really interesting when I was out for a meal at the weekend in a hotel restaurant and as we were having our main meal the head waiter came over and asked, *is everything ok?* I noticed myself automatically respond, *yes fine thanks*. I started to immediately think back to this rhetorical open-ended question. Why did the waiter do that? If my meal had not been nice would I have said so, or is the expected response *fine thanks*. How does this differ?

**How are you feeling? Demonstrating Presence: Combating Busyness**

I found some literature (Chapman, 1983; Byrne and Heyman, 1997) that will help me in my thinking surrounding the question how are you feeling, demonstrating presence. In actual fact it has been described as a strategy (not sure if this is correct word) by nurses to help them cope with their busyness. This is interestingly because children in this study talked about nurses asking them how they are whenever they are passing (on the go). So, this question/category demonstrating presence might sit opposite the category competing demands. Would it fit with humanistic qualities? Come back to review this.

# APPENDIX 38

# LATER ANALYTIC MEMOS

## Considering a Core Theme

What I am trying to do now is to re-juggle (for want of a better word) and consider the interlinking of the categories or dimensions I have under one core theme that will portray the essence of the thesis and what children are saying and I interpreted.

The core theme I feel is definitely visibility.

There are three sub-themes, being overshadowed, being at / brought to the forefront and making presence known, or not.

Being Overshadowed (child passive state): categories of this theme include things that parents and health professionals do that overshadow child or move the child to the overshadowed position from the forefront.

Categories include: *standing in the background, left in the dark and being blocked*

Being at / brought to the forefront (child active state): categories include things that parents and health professionals do that place child as forefront or assist in moving child to the forefront.

Categories include: *being invited into the conversation, being informed, being accommodated to.*

Making presence known, or not (child reactive state): in these categories the child reacts to either one or two of the above sub-themes and categories – this is where I am still having difficulty with – it is difficult to describe but it sits between the above two sub-themes.

Categories include: *bringing self to forefront, told because I asked and child adopting medical terminology and inventing child friendly language* ((?title))

I see the above concepts as appearing along a continuum, a visibility continuum, although I'm not really certain on this continuum, is this correct term, because it is not linear but rather in dynamic movement. It moves between two poles of *being overshadowed* and *being at the forefront*, with being overshadowed representing the invisible end and vice versa. The categories of these poles or sub-themes move the child back and forth along the continuum (this is essentially operated by health professionals and parents), but in between them is the sub-theme, making presence known, which is like the child's reactivity to the process.

For instance, the category standing in the background links vertically to being invited into conversation by bringing self to forefront and being uninformed links vertically to being informed by told because I asked. However the third set of categories don't really appear to link – need to look at these again that is being blocked, being accommodated to and child adopting medical terminology and inventing child friendly language, or do they? They link in terms of language and understanding but being blocked encompasses more than language and understanding.

What is missing from this is the category, competing demands, where does this sit?

I wonder is it like a weighing scales trying to achieve a balance between being overshadowed and being at forefront because I see these two extremes as equating with children's protection and participation rights. For example, why is all this happening?

Being overshadowed could be explained by fact child is not included / not informed / blocked because the HCP / parent think they are protecting child by withholding information and not exploring concerns (or are they protecting themselves). Being at the forefront would represent the opposite – participation rights.

Findings are similar to previous work in that they show aspect of child passivity and marginality in communication process. However, they also highlight an emerging pro-active aspect to include child but also child reactive in response to *being overshadowed* and attempt to move them selves to the forefront.

**Visibility as Core Theme**

The word 'visibility' as core theme – but is it only about being visible. Perhaps it is more about voice and hearing children. But looking at it in broader context what do I mean by visibility? Is it a way of seeing children? Is it how people see children and what they think about children? And this ultimately relates to how / if people hear children?

# APPENDIX 39

# PRELIMINARY THEMES, CATEGORIES AND PROPERTIES

| Theme | Categories | Properties |
|---|---|---|
| **Being overshadowed** | Standing in the background | Staff communicate with parents<br>Talking about child in his/her presence<br>Child eavesdropping |
| | Left in the dark | Not being told but wanting to know<br>Wanting to know more<br>Trustworthy information<br>Appropriate timing<br>What want to know |
| | Being blocked | Parents butt in<br>Closed questions<br>Habitual open questions<br>Big mad words<br>Premature reassurance<br>Changing topics<br>Not listening<br>Task / examination focus |
| **Being at / brought to the forefront** | Being invited into the conversation | Child allocated a turn<br>Open ended questions<br>Given opportunity to ask questions<br>Listened to |
| | Being informed | Staff give child information<br>Tell me as well as my parents<br>Parents give child information<br>Told everything wanted to know |
| | Being accommodating | Easy understandable words<br>Developmentally appropriate explanations<br>Using alternative tools / modes |
| **Making ones presence known (or not)** | Bringing self to forefront | Butting in<br>Asking questions<br>Converging to medical language<br>Inventing child friendly words |
| | Told because I asked | Wanting to know<br>Asking questions to find out |
| | Using parents | Asking parents questions<br>Parents help them understand<br>Using parents as link to staff |

# APPENDIX 40

# REVISED THEMES

| Visible-ness | Invisible: Being Overshadowed | Visible: Being at Forefront |
|---|---|---|
| **Process** | **Standing in the background** | **Invited into the conversation** |
| Directional flow of interaction – to child or parent or butting in of child or parent<br>Communication skills of HCP – listening, questioning, offering reassurance | Directional flow - staff communicate with parents<br>Talking about child in his/her presence<br>Child eavesdropping<br>Parents changed direction by butting in – if staff communicating with child<br>Staff use closed questions, ineffective listening skills and offer premature reassurance | Direction - child allocated a turn<br>Child changed direction by butting in – if staff communicating with parent<br>Staff use open-ended questions, give child an opportunity to ask questions and listen to child. |
| **Message** | **Left in the dark** | **Being Informed** |
| Information exchanged and its comprehension (what, who, how, when, etc of information exchange and its understandability) | Not being told but wanting to know (uninformed)<br>Wanting to know more (inadequate information)<br>Inability to understand message – incomprehensible<br>Maintaining optimistic assertion<br>Prefer to be left in the dark (not wanting to know)<br>What children want to know<br>Trustworthy information<br>Appropriate timing<br>Children adopting medical terminology | Staff give child information<br>Information hierarchy<br>Doctor as knowledgeable expert<br>Nurse intermediary role<br>Tell me as well as my parents<br>Parents intermediary role (using parent/reliant on parent)<br>Comprehensible information<br>Child navigates own information – told because I asked (child asking questions)<br>Children inventing own terminology |
| **Context** | **Competing Demands** | **Humanistic Qualities** |
| Intrinsic environmental context and innate personal health professional qualities which created the ward ambience | Busy task oriented health professionals<br>Inaccessible health professionals<br>Not making presence known<br>Busy pre-occupied children<br>Occupational play v therapeutic<br>Technology and play | Nice, friendly, humorous staff<br>Not nice<br>Demonstration of staff presence and acknowledge child presence |

# APPENDIX 41

# COMMUNICATION ASSESSMENT GUIDELINES

**Assessment Sheet Guidelines**
"The following are examples of the kind of information that needs to be obtained from the child and/or the family" (Smith, 1995:70)

Communication (page 74)

| | |
|---|---|
| Sight | Formal tests/infant follows light, bright objects, people. Glasses/contact lenses – when worn. Blindness – hereditary, partial/total. Colour blindness. Injury, blurred vision, headache, intolerance to light. |
| Hearing | Tests/turns or startles with noise/voice. Hearing aids. Deafness – lip reads, etc. Grommets/glue ear, any treatment in progress. Reduced ability, ear injury, discharge/oozing. |
| Speech | Language – English/Punjabi/Italian, vocalization level – babbles, small vocabulary. Speech difficulties – lisps, etc. attends speech therapy. Sign language – type, Markerton, etc. Other methods of communication. |

**Guidelines for the 'On Admission' section**
"The child's Activities of Living on admission or transfer may differ from his/her usual activities and it is these differences that should be recorded in this section" (Smith, 1995:80)

Communication (page 82)

| | |
|---|---|
| Speech | Appropriateness of words used. Abusive, babbling, sobbing. Interpreter required.<br>Body language – watchful.<br>Shy, unspeaking. |
| Hearing | Reduced ability.<br>Ear injury.<br>Discharge, oozing. |
| Sight | Injury.<br>Blurred vision.<br>Headache.<br>Intolerance to light. |

**Examples of what to write, given within Smith's (1995) textbook:**

Jimmy aged 18 months, admitted with febrile convulsion

COMMUNICATION

"PASSED FORMAL HEARING TEST. OBEYS SIMPLE INSTRUCTIONS. FIXES & POINTS TO DISTANT OBJECTS. COMMUNICATES NEEDS BY POINTING. 'JABBERS' LOUDLY. USES 10 RECOGNISABLE WORDS BUT UNDERSTANDS MORE.
SINGS AND JOINS IN NURSERY RYHMES"

.....

On Admission
CRYING & IRRITABLE
CLINGING TO HIS MUM
(Smith, 1995:94 handwritten)

Clare aged 10 weeks admitted with apnoeic episode

COMMUNICATION

"BABBLES, SMILES & SQUEALS WHEN EXCITED. CRIES IF LOUD SUDDEN NOISES OR IF UNCOMFORTABLE
SMILES AT SOUND OF MOTHER'S VOICE
TURNS HEAD TOWARDS MUM & DAD. WATCHES MOBILE. RECOGNISES MUM & DAD.

.....

On Admission
WATCHING MOTHER TALKING & COOING"
(Smith, 1995:105 handwritten)

# APPENDIX 42

# FORCES INFLUENCING THE POSITIONING OF CHILDREN IN THE COMMUNICATION PROCESS

**Forces influencing the position of children in the communication process**

| FORCE | Protection | Participation | PROTECTION-PARTICIPATION |
|---|---|---|---|
| Social position of children in society | Children as "becoming" | Children as "being" | Children as both "becoming" and "being" |
| Children's rights | Protectionist<br>Children right to be protected / in need of adult protection | Liberationist<br>Children have right to actively participate and exercise autonomy | Pragmatist<br>Children in need of protection / support and active participants / autonomous beings |
| Children's development | Children immature, irrational, incompetent and progress through universal processes of growth, socialised to adulthood<br>Dependent children | Children are competent actors, responsibility transferred to child<br>Independent children | Children grow in competence through participation, sometimes working in collaboration with others and other times working independently<br>Interdependent children |
| Power relations | Children are powerless<br>Adults hold power over children | Children are empowered<br>Adults relegate power to children | Power around - adults hold power, children also powerful |
| Family-centred care | Family at the heart of care, single unified parent-child entity<br>Focus on parent participation/partnership to address child's psychosocial needs | Absence/exclusion of parents<br>Child as unique entity | Caring for both child and family, recognised both as unique and collective entities<br>Parents presence protects psychosocial needs of children but also supports children's participation |
| Communication process | Communication takes place with parent. Child holds a passive subordinate role.<br>Child placed in the background, overshadowed. | Communication takes place directly with child. Child is an active participant. Child placed at forefront. | Communication takes place with both child and his/her parent. Child wants to be involved but also values support of parent. At times, prefer to be in the background overshadowed, other times want to be at forefront. |